Adaptation of the Carers' Alert Thermometer (CAT) for use with the family caregivers of stroke survivors (CAT-S): An action research study.

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March 2020

A thesis submitted in partial fulfilment of the requirements for

the degree of Doctor of Philosophy

Edge Hill University

Declaration

This thesis is entirely my own work and has not been submitted in full or part for the award of a higher degree at any other educational institution. Parts of the PhD have been discussed and presented prior to submission of the thesis and these are detailed below:

Conferences

MALEWEZI, E., 2019. Poster Presentation: Adaptation of the Carers' Alert Thermometer (CAT) to develop the CAT-S for use with family caregivers of stroke survivors. Post-Graduate Research Student Symposium at Edge Hill University, 14th May.

MALEWEZI, E., 2017. Poster Presentation: Assessing the needs of family caregivers of stroke survivors: findings from phase one. Post-Graduate Research Student Symposium at Edge Hill University, 18th June.

MALEWEZI, E., O'BRIEN, M., THOMAS, J., JACK, B., 2016. Poster Presentation: Assessing the needs of stroke family caregivers: Adapting the CAT to develop the CAT-S. 11th UK Stroke Forum (Liverpool) 28th - 30th December.

MALEWEZI, E., 2016. Oral Presentation: Adapting the CAT to develop the CAT-S: An action Research study: Post-Graduate Research Student Symposium at Edge Hill University, 17th May.

MALEWEZI, E., 2015. Oral Presentation: Action Research. Post-Graduate Research Student Symposium at Edge Hill University, 18th June.

Acknowledgements

I would like to express my gratitude to a number of people who have offered me unconditional support throughout my PhD to make this thesis possible. In the first instance, I would like to extend my thanks to all stroke family caregivers and staff working within various stroke services in the UK who participated in this study. Special thanks go to members of the virtual action research group (VAG) for providing their views and feedback in the different phases of this study and staff at the Stroke Association for their assistance in recruiting this study's participants.

I also owe a great deal of thanks to my supervisors: Prof. Barbara Jack, Prof. Mary O'Brien, Dr. Juliet Thomas and Dr. Katherine Knighting (specialist Delphi advisor). I cannot find the right words to convey my gratitude for all your support and patience, particularly during the times that I almost felt like giving up. Special thanks are also directed towards my PhD and work colleagues: Olly, Greg, Amy, Mellissa and Lynn. Thank you for keeping me motivated throughout my PhD. To my parents, brothers and sisters, thank you for your emotional support.

To my husband Justin, I couldn't have pursued this PhD without your support, thank you for everything. To my children Leoni and Mayambo, thank you for your patience and prayers. May you follow your dreams. Lastly, I thank the Almighty God. Philippians 4 verse 13*: 'I can do all things through Christ who strengthens me'.*

Dedication

I would like to dedicate this thesis to two very special people. My dad (Francis) a stroke survivor, and my aunt (Alexina) who died on the day I attended the PhD interview at Edge Hill University.

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Preface

I would like to commence this thesis by explaining how I developed an interest in the medical condition of stroke and ended up conducting this study. I personally became aware of the impact of having the condition when my dad suffered a stroke at the age of 53 due to untreated hypertension. At the time, I was a final year diploma nursing student at the University of Malawi (Africa). I vividly remember the day he suffered his stroke; it was sudden and came as a shock to the whole family. He had just had his lunch and was seated in the car about to return to work. He could not walk; his speech was slurred. The assessment conducted by doctors at the nearest hospital in Lilongwe, the capital city of Malawi, confirmed that he had suffered a stroke. He was immediately started on antiplatelet therapy (Aspirin) without having a brain scan, which is common practice in low-income countries like Malawi, where imaging equipment, such as CT scanners, is not available in most hospitals. The following day, through arrangements made by his employers (an international organisation) he was transferred to another city in the country, about 400 km away, to have a brain scan.

The brain scan confirmed a haemorrhagic stroke and his Aspirin was immediately discontinued. Because of the impairments caused by the stroke, my dad could not continue with his employment and subsequently took early retirement. Six months later, my maternal grandmother also suffered a stroke at the age of 80. Suddenly, my mother became a family caregiver for both my dad and my grandmother. My grandmother died in 2012, twelve years after her stroke. My dad is still alive 19 years after his stroke.

My interest in the medical speciality of stroke originated from these early experiences in my life. After qualifying as a nurse, I had the desire to pursue further studies. At the time, nurses had to work for two years, prior to being accepted to undertake a degree

in nursing at the University of Malawi. It was at this point that my dad took his pension savings and paid for my school fees to come to England as an international student and pursue a degree in nursing, specialising in stroke nursing.

After completing my degree in nursing in 2001, I was offered a job as a staff nurse on the stroke unit at a hospital in London. Since then, I have worked in various capacities within stroke services, from being a staff nurse to becoming a Clinical Nurse Specialist (CNS) in stroke, as well as being the Stroke Unit Manager. During this period, I witnessed how stroke care and treatment improved as a result of evidence from research. I undertook various postgraduate courses and completed my MSc degree in nursing. However, my interest in conducting research with stroke family caregivers originated from the numerous conversations that I held with stroke survivors and their family caregivers during the nurse-led follow up clinic consultations. It was apparent during these conversations that most stroke family caregivers experience challenges in their caregiving role.

I therefore applied for a PhD studentship at Edge Hill University in 2014 and was successful in obtaining a position. After working in the National Health Service (NHS) for 13 years, I took a career break from my role as a Senior Clinical Sister for stroke in London, which was a dual role of managing the Stroke Unit and running a nurse-led stroke follow-up clinic, to become a full- time student. As a stroke nurse, my main goal was to explore practical solutions that could possibly alleviate the challenges experienced by stroke family caregivers. These past personal experiences and particularly, my professional background, informed the undertaking of this study underpinned by principles of action research.

Abstract

Background

An estimated 1.2 million stroke survivors living in the United Kingdom (UK), currently rely on family caregivers for daily support. The needs of stroke family caregivers are not routinely assessed by most stroke services. An early identification of their needs and support is crucial to maintain their well-being and caregiver role. At present, stroke-specific caregiver screening tools are lacking.

Aim

To adapt the Carers' Alert Thermometer (CAT), a short screening tool developed in the context of end-of-life care and develop the CAT-S for use with stroke family caregivers.

Methods

This was a multi-phase study, underpinned by principles of action research. Between February 2016 to December 2017 qualitative and quantitative data were collected sequentially from purposive samples of stroke family caregivers (n=76) and staff working within stroke services (n=238) in the UK. Semi-structured interviews were conducted to inform the contents of the CAT-S. Key items for inclusion were identified through a modified Delphi survey and consultation with an expert panel. The CAT-S was then piloted in North West England to test its usability and usefulness in practice to identify the needs of family caregivers of stroke survivors. Thematic analysis and content analysis were used to analyse qualitative data. Quantitative data were analysed using descriptive statistics.

Findings

The CAT-S comprises the key challenges that are experienced by stroke family caregivers. Additional items that were not present on the original CAT were identified and included. These were the training needs of family caregivers to provide care and support for their emotional needs. The CAT-S was found to be useful and acceptable by both staff and stroke family caregivers and resulted in action plans and support being provided. The CAT-S is a potentially valuable tool in prioritising family caregivers requiring comprehensive assessments.

Key words

Stroke, caregiver, assessment tool, screening tool, needs, support, Delphi technique, action research.

Chapter 1: Background

1.1 Introduction

The aim of this research was to adapt the Carers' Alert Thermometer (CAT) and develop the CAT-S for use with the family caregivers of stroke survivors. To provide context to this study, the background chapter provides an overview of the original CAT and introduces the medical condition of stroke, presenting a definition, prevalence, associated risk factors and a brief explanation on the management and treatment available to individuals who survive a stroke. The role undertaken by family caregivers in supporting stroke survivors is discussed, prior to exploring the literature regarding their experiences and the support available to family caregivers in the United Kingdom (UK).

1.2 The Carers' Alert Thermometer (CAT)

The CAT is a short screening tool that was developed by researchers from Edge Hill University in collaboration with colleagues from the Universities of Liverpool and Sheffield (Knighting et al., 2015, 2016) (Appendix 1). The project was funded by a grant from the National Institute for Health Research (NIHR) to identify and support the needs of the unpaid caregivers of patients with cancer and advanced progressive illnesses providing end-of-life care at home (Knighting et al., 2015; 2016). The CAT was developed based on the concept of the modified early warning system (MEWS), which is utilised by healthcare professionals to assist in the identification of deteriorating patients and ensure the timely escalation of care (Subbe et al., 2001). Developed as a screening tool, the CAT is for use by non-specialist staff and acts as

an alert to the need of family caregivers providing end-of-life care at home. Additionally, the CAT assists in prioritising family caregivers requiring a formal assessment to be undertaken by experienced professionals (Knighting et al., 2015, 2016). The CAT consists of 10 questions that fall under two main topics. The first topic is the current caring situation and explores the needs of caregivers in their caregiving role and the second topic explores the caregivers' own health and well-being. It uses the traffic light system to score the risk of alerts (low risk (green), medium (amber), high (red)) and an image of a thermometer to mark the number and type of alerts. This provides a quick visual representation of the extent of the caregivers' needs. It is recommended that the alerts scored as high (red) are given priority for action. There is a 'next steps' section, which can be tailored to include the local services that the caregiver can be signposted to and an action plan used to trigger intervention as appropriate to be jointly agreed by the assessor and the caregiver.

Since its launch in September 2014, the CAT is freely available for non-profit use at: www.edgehill.ac.uk/carers/cat-registration [Accessed 10 March 2020]. So far, 458 individuals from 15 countries have registered to access the CAT and its resources. However, the exact number of individuals using it is unknown. In the United Kingdom (UK), the CAT was piloted at the Clatterbridge Cancer Centre and Motor Neurone Disease (MND) Association in the South West and North West of England. Currently, it has been adopted by and being rolled out across the MND Association for England and Wales and Northern Ireland. A pilot for its use is ongoing with MND Scotland. Furthermore, another CAT specifically designed for use with young caregivers (CAT-YC) is being developed at Edge Hill University. The feedback received from family

caregivers and health and social care professionals suggests that the CAT is quick and easy to use and will be important in helping to identify caregivers' needs and to provide signposting to appropriate services (Knighting et al., 2015).

1.3 Overview of stroke

1.3.1 Definition and types of stroke

Stroke has been described as an acute neurologic dysfunction of vascular origin with rapidly developing clinical signs of focal or global disturbance of cerebral function, lasting more than 24 hours (World Health Organisation (WHO), 1988). The term 'Cerebrovascular Accident' (CVA) is also utilised in the medical literature to refer to stroke, however, the use of this term has been discouraged by some clinicians and perceived to be misleading to patients and their families and not reflecting current policy (Sibson and Khadjooi, 2017). The connotation carried by the term 'accident' inadequately highlights the modifiability of the underlying risk factors for stroke (Brown, 2002; Scadding and Losseff, 2011; Kaufman, Myland and Milstein, 2012). In the last decade, the term 'brain attack' has been used to describe stroke, due to the sudden onset of symptoms, and the need to act promptly in view of advances in treatment options, such as thrombolysis (Department of Health (DH), 2007; National Institute for Health and Clinical Excellence (NICE), 2008). The term stroke will, however, be used throughout this thesis due to its widespread usage among clinicians and the public.

The two main types of stroke are ischaemic and haemorrhagic stroke. Ischaemic stroke is caused by blood clots blocking arteries in the neck or the brain and accounts for 85% of stroke cases; haemorrhagic stroke results from arterial bleeding into

(intracranial) or around (subarachnoid) the brain and accounts for 15% of stroke cases (Luengo-Fernandez et al., 2013; Intercollegiate Stroke Working Party (ISWP), 2016). Differentiation between ischaemic and haemorrhagic stroke based solely on clinical signs is unreliable and thus urgent brain imaging is necessary to confirm diagnosis and determine a treatment plan. Transient ischaemic attack (TIA), also known as minor stroke, occurs when stroke symptoms resolve themselves within 24 hours.

1.3.2 Incidence and prevalence

On a global scale, 17 million people suffer a stroke annually (Feigin et al., 2014) and it is the second most common cause of death in the world, responsible for around 6.7 million deaths each year (WHO, 2017). Over 100,000 people have a stroke every year in the UK, making it the fourth leading cause of death and the largest single cause of adult disability (Royal College of Physicians (RCP), 2017). According to the Stroke Association's state of the nation report, stroke accounted for 38,000 deaths in the UK in 2016, thus representing 7% of all deaths (Stroke Association, 2018). Although most people will survive their first stroke, they are often left with a major disability (Feigin et al., 2014). Furthermore, stroke survivors are at a particularly high risk of subsequent cardiovascular events including a recurrent stroke, myocardial infarction and death from vascular causes (Hackam and Spence, 2007; Elkind, 2009).

Stroke can occur in individuals of any age including children, however, nearly three-quarters of cases occur in people over the age of 65 (National Audit Office (NAO), 2010). Evidence suggests that the incidence of major stroke is declining in many high-income countries (Feigin et al., 2014). This decline has been attributed to

improvements in the primary prevention of stroke, such as aggressive approaches to reducing hypertension, hypercholesterolemia and smoking (Rothwell et al., 2004; Spence and Barnett, 2012). Nevertheless, with the ageing population, it is proposed that the number of people at risk of stroke will continue to rise (Di Carlo, 2009). Additionally, current estimates suggest that due to demographic changes, the rate of first-time strokes in people aged 45 and over is expected to increase by 59% in the next 20 years with the number of stroke survivors aged 45 and above living in the UK also expected to rise by 123% (Patel et al., 2017). The UK government has recognised stroke as a major health condition and included it in the recent NHS long-term plan (NHS England, 2019). In addition, stroke places a significant burden on the economy. It is estimated to cost the UK £26 billion per year, with informal care provided by family and friends accounting for about 57%, while 30% of this sum are costs to the NHS, 11% social care and 3% lost productivity (Patel et al., 2017). At present, there are approximately 1.2 million stroke survivors living in the UK (Stroke Association, 2018).

1.3.3 Stroke risk factors

Stroke is associated with numerous risk factors, which are normally categorised as non-modifiable and modifiable (Table 1). Non-modifiable risk factors include age, sex, ethnicity and family history of stroke (Spence and Barnett, 2012; Jones and Jones, 2017). Stroke incidence increases markedly with age. The risk of stroke doubles with each decade of increased age after 55 years of age (Rothwell et al., 2004; Romero, Morris and Pikula, 2008). Men appear to have a higher risk of stroke than women and experience stroke at a younger age (RCP, 2017). Compared with Caucasians, people of African origin have a higher risk of all strokes (Kleindorfer et al., 2006; Lindgren,

2014). Possible explanations include poor management of the treatable risk factors of stroke. Family history of stroke also appears to be related to its incidence, particularly if a first-degree blood relative has stroke before the age of 55 (Bevan et al., 2012). Other rare stroke syndromes have been associated with mono-genetic variations, such as cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL) and mitochondrial myopathy encephalopathy, lactic acidosis and stroke-like episodes (MELAS) (Cole and Gutwald, 2013). Although these risk factors are classed as non-modifiable, it may be important to ensure that individuals with these risk factors have appropriate primary prevention strategies in place given their higher risk of stroke.

Modifiable risk factors, such as hypertension, diabetes mellitus, atrial fibrillation, hypercholesterolemia and TIA, will require active medication management combined with lifestyle adjustments (NICE, 2008; Goldstein et al., 2011). Smoking, excessive alcohol intake, lack of exercise, poor diet and illegal drug use, such as cocaine, are other risk factors of stroke that can be countered by patient education and other government-led public health strategies (Lindgren, 2014; ISWP, 2016). In the UK, the National Institute for Health and Care Excellence (NICE), recommends individuals over the age of 40 to undergo regular cardiovascular risk assessments to identify people at high risk and initiate primary prevention strategies (NICE, 2014).

Table 1: Modifiable and non-modifiable risk factors for stroke

Modifiable risk factors	Non-modifiable risk factors
Hypertension	Age
Diabetes mellitus	Gender (Male sex)
Atrial fibrillation	Ethnicity
Smoking	Family history of stroke
Alcohol (> 30 units /week)	
Physical inactivity	
Obesity	
Abnormal blood lipids	
Poor diet (high fat; low fruit and vegetables intake)	
Migraine	
Transient ischaemic attack (TIA)	
Illegal drugs (e.g. cocaine)	

1.3.4 Diagnosis

Stroke is diagnosed through a combination of thorough clinical examination and the description of the sudden onset of the focal neurological function that is thought to be due to disturbed blood supply to the relevant part of the brain, retina or spinal cord (Hankey and Blacker, 2015). Nevertheless, the diagnosis of stroke is confirmed by brain imaging (computed tomography or magnetic resonance imaging) (Sacco et al., 2013). Stroke guidelines recommend that all patients with a suspected stroke should receive a brain scan within one hour of arriving at the hospital (ISWP, 2016). In the last decade, there has been a radical shift in attitudes towards the management of stroke. Previously given low priority within the National Health Service (NHS) and viewed as an inevitable outcome of ageing, stroke is now seen as an acute disease

event in which swift and appropriate treatment can induce major benefits in terms of patient outcomes (DH, 2007; NICE, 2008; NAO, 2010).

Additionally, the use of simple scales, such as the Face, Arm, Speech Time test (Figure 1) (Harbison et al., 2003; ISWP, 2016), aids in the rapid identification of patients with possible stroke or TIA in the community. Typical symptoms of stroke include the sudden onset of paralysis or loss of muscle control usually on one side of the body, altered speech, problems with memory and concentration; difficulties with swallowing, visual problems and bladder or bowel dysfunction. Other associated effects of stroke commonly experienced by survivors include depression, emotionalism, fatigue and lack of confidence (Rowe, 2013; Ayerbe et al., 2015; IWSP, 2016). The degree and type of disability that follows depends on the artery affected and the damaged areas of the brain.

Figure 1: Face, Arm, Speech and Time (FAST) test (Harbison et al., 2003; Stroke Association, 2018).

Face – Ask the person to smile. Does one side of the face droop?
Arms – Ask the person to raise both arms. Does one arm drift downward?
Speech – Ask the person to repeat a simple phrase. Is the speech slurred or strange?
Time – If you observe any of these signs, call for an ambulance immediately.

1.4 Management and treatment

1.4.1 Organised stroke unit care

In high-income countries such as the UK, evidence suggests that stroke unit care increases the likelihood of the stroke survivor being discharged home and reduces death and dependence compared to care in a general ward (Stroke Unit Trialists' Collaboration (SUTC), 1997, 2013). These benefits are seen regardless of the patient's age, gender, stroke type (ischaemic or haemorrhagic) or severity. Factors associated with the improved outcomes include effective communication (O'Rouke and Walsh, 2010) and a patient review by a stroke consultant within 24 hours of hospital admission, formal swallow assessment and prevention of complications by the stroke multidisciplinary team (Bray et al., 2013). National and international stroke guidelines, therefore, recommend that all acute stroke patients should be treated on a stroke unit throughout their inpatient stay unless stroke is not the predominant medical problem (ISWP, 2016).

1.4.2 Specific treatments for acute ischaemic stroke

Thrombolysis

Thrombolysis (clot-busting treatment) with intravenous recombinant tissue plasminogen activator (rt-PA) is the recommended treatment for acute ischaemic stroke. This treatment has been shown to improve outcomes in patients meeting the criteria for administration within four and a half hours of symptom onset (NICE 2012; ISWP, 2016). The proportional benefits of intravenous rt-PA are greater with earlier treatment; therefore, timely assessment and management are critical. The time of

symptom onset, to the time taken to arrive to the hospital (onset to arrival time) and the time from arriving at the hospital to being thrombolysed (door to needle time) are thus important to improve patient outcomes. This treatment is, however, administered in specialist centres which have sufficient infrastructure and expertise, such as hyper-acute stroke units (HASU) (ISWP, 2016).

Thrombectomy

Mechanical thrombectomy is a relatively new treatment in the UK for people suffering a severe stroke, licensed to treat large-vessel occlusion (NHS England, 2017). This treatment consists of intra-arterial catheterisation to the level of occlusion followed by delivery of a thrombolytic agent, mechanical thrombectomy or both in specialist neuroscience centres. The procedure is conducted with either local or general anaesthetic and is recommended to be given within five hours of symptom onset in patients with a National Institute of Health Stroke Scale (NIHSS) score of six or more (NICE, 2016; ISWP, 2016). Evidence suggest that thrombectomy is beneficial for carefully selected patients with a severe stroke due to proximal arterial occlusion and in whom recanalisation can be achieved within 6 hours of symptom onset (Rodrigues et al., 2016). This treatment is currently available in about 107 out of 158 sites in the UK that treat stroke patients in the first 72 hours either on-site or by referral with plans for expansion underway to ensure that the treatment is widely available (RCP, 2016).

Decompressive hemicraniectomy

Although rare, ‘malignant’ middle cerebral artery (MCA) infarction is a life- threatening complication of stroke, usually occurring in people without brain atrophy, where space-

occupying brain oedema presents within two to five days of stroke onset (Woodward and Mestecky, 2011). Decompressive hemicraniectomy (DH) involves the removal of the fronto-parieto-temporal section of the cranium, thereby allowing space to accommodate the oedematous brain, reducing the possibility of death and improving patient functional outcomes (Rieke et al., 1995; Vahedi et al., 2007). Stroke guidelines in the UK thus recommend that patients with MCA infarction meeting a specified criterion should be considered for DH and referred to neurosurgery within 24 hours of stroke onset and treated within 48 hours of stroke onset (ISWP, 2016). Survivors of malignant MCA infarction typically have wide- ranging impairments and are highly debilitated (McKenna et al., 2012).

1.4.3 Specific treatments for haemorrhagic stroke

Treatment for acute haemorrhagic strokes, which account for 15% of strokes, depends on the associated causes of the haemorrhage and the level and location of the bleed. All patients suffering intracranial haemorrhage (ICH) require specialist monitoring in a neurosurgical centre or HASU with access to brain imaging.

Surgical treatment of acute intracerebral haemorrhage

Following stroke, surgical intervention may be beneficial for patients meeting a specified criterion including patients with a very large haematoma and where a structural cause of bleeding is identified following brain imaging. In such instances, immediate surgery to evacuate the haematoma is recommended (ISWP, 2016). Furthermore, patients with intracranial haemorrhage who develop hydrocephalus should be considered for surgical intervention, such

as insertion of an external ventricular drain (ISWP, 2016). This helps to relieve pressure and prevent death.

Medical management

The management of haemorrhagic stroke remains a challenge since surgical treatment has yet to be shown to be more effective than non-surgical interventions and no drug therapy has yet achieved a difference in the three- month outcome of this condition (Broderick et al., 2007). Early identification of concurrent coagulopathy (bleeding disorder) is vital to determine the need for additional treatment to support or augment the clotting cascade (ISWP, 2016). Treatment options may include immediate cessation of direct oral anticoagulants and consideration of specific reversal agents for acute intracerebral haemorrhage associated with certain types of oral anticoagulants (Hankey, 2017). Furthermore, current evidence suggests that elevated blood pressure may exacerbate haemorrhage expansion (Tsivgoulis et al., 2014; Qureshi et al., 2016). Patients with primary intracerebral haemorrhage who present within six hours of onset with a systolic blood pressure above 150mmHg should therefore be treated urgently using locally agreed protocols for blood pressure management. The aim is to achieve a systolic blood pressure of 140mmHg or less within the first seven days (ISWP, 2016).

1.4.4 Secondary prevention of stroke

The long-term risk of recurrent stroke is around 10% at 1 year, 25% at 5 years and 40% at 10 years (Mohan et al., 2011). Measures for secondary prevention must therefore be implemented soon after the diagnosis of stroke is confirmed. This may

include antiplatelet medications for ischaemic stroke (unless contraindicated), management of hypertension with anti-hypertensive medication, statin treatment in eligible patients and anticoagulation in the context of atrial fibrillation, which is normally delayed for up to two weeks due to the risk of haemorrhagic transformation (Field and Benavente, 2016; ISWP, 2016). In patients with diabetes or glucose intolerance, individualised lifestyle modification and pharmacological therapy in line with existing guidelines for glycaemic control are recommended (Kernan et al., 2014). Additionally, ensuring the identification and modification of all risk factors, including lifestyle issues, leads to more effective secondary prevention of stroke and other vascular events (Lawrence et al., 2011). Recommendations include smoking cessation, health promoting behaviours, such as exercise, weight loss, healthy diet and reduced alcohol intake, yet compliance requires ongoing monitoring and reinforcement (ISWP, 2016).

1.4.5 Stroke rehabilitation and recovery

Following a stroke, most survivors embark on a rehabilitation journey, which has been described as a progressive, dynamic, goal-orientated process aimed at enabling individuals with impairment to reach their optimal physical, cognitive, emotional, communicative, social and functional activity level (Herbert et al., 2016). National stroke guidelines recommend that all individuals entering a period of rehabilitation should be screened for common impairments and should have realistic goals set (ISWP, 2012; ISWP 2016). The rate of recovery varies for different impairments, disabilities and individuals, however, the basic principles that should be applied throughout the rehabilitation of individuals following stroke include:

1. Documentation of impairments, disabilities and handicaps, where possible measuring them using simple, valid scales.
2. Maximisation of independence and minimisation of learned dependency.
3. Adoption of a holistic approach to individuals that incorporates their physical and psychosocial background support mechanism and environment.
4. Supporting caregivers and helping them to develop physical and psychological skills to provide long-term sustainable support to stroke survivors (Karla, 2012).

Early supported discharge from hospital

Over the past few years, evidence from a Cochrane review indicates that early supported discharge (ESD) services reduce the length of hospital stay, admission to institutional care and long-term dependency in stroke survivors with mild to moderate impairments (Fearon et al., 2012). ESD services consist of specialist members of the multidisciplinary team (such as doctors, nurses, occupational therapists, physiotherapist, speech and language therapists) that provide rehabilitation to individuals at home at the same intensity and skill mix as the stroke unit. This enables stroke survivors to return home from hospital earlier than usual and continue rehabilitation in the familiar environment of their own home at their own pace (Lou et al., 2017a). In the UK, national stroke guidelines recommend that following hospital admission, patients with stroke who have mild to moderate disability should be offered ESD with treatment at home, beginning within 24 hours of discharge from hospital (NICE, 2013; 2016). The duration of the ESD input varies depending on patient needs although some services have a maximum length of input after which stroke survivors are transferred to the care of community stroke rehabilitation teams and receive

continued support from their family caregivers.

1.5 Family caregivers

1.5.1 Terminology and definition

Different types of caregivers exist; some with paid and others with unpaid roles. The focus of this study is unpaid caregivers who are normally family members or friends. To differentiate between those in paid and unpaid roles, the prefix ‘family’ or ‘informal’ is usually added to the words carer or caregiver (Moriarty, 2012). The term ‘carer’ is more common in the UK; however, the term ‘caregiver’ appears more frequently in the literature. The term ‘family caregiver’ will therefore be used throughout this thesis to describe this group of people.

According to the UK government, a ‘family caregiver’ has been defined as ‘someone who looks after and supports a friend, relative or neighbour who could not manage without their help. This could be due to age, physical or mental illness or disability’ (Directgov, 2011: 1). Excluded from this definition are professionals or other people who provide care under a contract, as part of employment or voluntary work (British Parliament, 2014). Around the globe, family caregivers form the backbone of most health and social care systems. For instance, in a survey that was conducted in Canada by the Canadian Institute for Health Information (CIHI), around 98% (n=131,000) of home care clients required the support of family caregivers with a wide range of activities including meal preparation, bathing and toileting (CIHI, 2010). In Australia, the findings from a report commissioned by the government estimated that family caregivers save taxpayers 60.3 billion Australian dollars annually, or in other

words cover the cost of replacing caregivers providing informal care with paid care workers (Deloitte Access Economics (DAE), 2015). Similarly, in America, the value of the services provided by family caregivers increased to an estimated value of 470 billion US dollars in 2013 up from 375 billion US dollars in 2007 (Reinhard et al., 2015).

1.5.2 Overview of family caregivers in the UK

In the UK, the 2011 UK census data indicate that there are currently 6.5 million family caregivers representing approximately 12% of the overall population (Office for National Statistics (ONS), 2011). With an aging population, this figure is predicted to rise to 9 million by 2037 (Care UK, 2015). Some authors argue that the official figures and estimates could be underestimated due to most individuals not identifying themselves as family caregivers (Carduff et al., 2014). However, family caregivers are not a stationary population; over 2.1 million adults become caregivers every year and almost as many people find that their caring responsibilities cease as the person they care for recovers, moves into residential care or dies (Hirst, 2014). This turnover means that caregiving will affect the lives of most individuals as they will be required to provide care or support family members at some point in their lives.

Similar to other parts of the world, most family caregivers in the UK are female (58%); with over 2 million people in the 50-64 age group (ONS, 2011). A report by Carers UK revealed that the number of family caregivers over the age of 65 is also increasing, with a more rapid growth in the group of caregivers aged 85 and over, whose numbers have risen by 128% in just 10 years (Carers UK, 2015). Almost half of the caregivers in the UK combine employment and caregiving; over two million caregivers work full-

time and one million part-time (ONS, 2011). There is also evidence to suggest that multigenerational caring is on the increase. There are approximately 2.4 million people who are ‘sandwich caregivers’, i.e. caring for an older adult at the same time as caring for their children (YouGov Poll, 2012). Additionally, in expanding the concept of the sandwich generation, the literature highlights a population of older adult family caregivers termed ‘panini sandwich’ caregivers (Abramson, 2015). These are family caregivers sandwiched between their own aging needs or age-related changes and providing care.

The amount of care that family caregivers provide varies considerably ranging from a few hours of care a week to caring around the clock. Nearly 4 million family caregivers provide care for up to 19 hours a week; 1.4 million provide care for over 50 hours a week, whereas the remaining 1.1 million provide care for 20 to 49 hours week (Buckner and Yeandle, 2015; Carers UK, 2015). According to the NHS Information Centre Survey of Carers in Households (2010), 82% of family caregivers provide practical help such as preparing meals, doing laundry or shopping, whereas 76% keep an eye on the person they care for and 38% provide personal care. About 71% of family caregivers provide personal care such as washing, dressing, eating or using the toilet. Better methods of supporting all types of family caregivers are therefore required if their vital role is to be sustained (Carers UK, 2015).

1.5.3 Family caregivers of stroke survivors

Despite the evidence-based treatments discussed in the previous sections of this chapter, most stroke survivors have disabilities that prevent them from functioning

independently in the community without additional support. In England, Northern Ireland and Wales, around 84% of individuals are discharged from hospital to home and subsequently require support with their activities of daily living mostly from family caregivers (RCP, 2017). Family caregivers play a critical role in maintaining the physical, psychological and social well-being of stroke survivors (Shanmugham et al., 2009). Furthermore, they undertake domestic responsibilities previously performed by the stroke survivor as well as taking on added responsibilities related to the stroke survivors' treatment, such as driving them to hospital appointments and other community-based activities (Tooth et al., 2005; Simeone et al., 2016). Although each illness presents specific challenges for family caregivers, some authors suggest that the family caregivers of stroke survivors are unique due to the sudden and unexpected onset of stroke resulting in an abrupt uptake of the caregiving role (Lincoln et al., 2011). The authors argue that although other cardiovascular conditions such as heart attack may have a sudden onset, they do not have extensive neurological consequences.

In addition, evidence from research has demonstrated that family caregivers also play an important role in facilitating the recovery of stroke survivors. For instance, notable improvements in hemispatial neglect (a disorder where a patient has reduced awareness to one side of their body or environment following brain conditions such as stroke) and mobility have been observed in stroke survivors who involved family caregivers in their rehabilitation programmes compared to stroke survivors who received rehabilitation without the participation of their family members (Osawa and Maeshima, 2010). Similarly, shorter lengths of hospital stay and higher rates of stroke survivors returning home following hospital discharge have been observed among

stroke survivors who involved family members in their rehabilitation programs (Hirano et al., 2012). On the contrary, poor quality of life in family caregivers is associated with the rehospitalisation of the stroke survivor and increased healthcare costs (Low, Payne and Roderick, 1999; Chau et al., 2014).

Negative experiences of stroke family caregivers

The sudden nature of stroke and the absence of a gradual transition into the caregiving role is challenging for most family caregivers since it leaves little time for the acquisition of skills and information to support the successful recovery of stroke survivors (Mackenzie et al., 2007). High rates of stress- related psychological problems, such as depression and anxiety have been reported in the family caregivers of stroke survivors (Han and Haley, 1999; Draper and Brocklehurst, 2007; Wilz and Kalytta, 2008). In a survey conducted by the Stroke Association (UK), 64% of stroke family caregivers reported that the emotional impact of stroke was the most significant challenge that they had experienced (Stroke Association, 2013). Even with paid formal assistance, the family caregivers of stroke survivors are frequently faced with a multitude of stressors ranging from the coordination of medical appointments to in some instances 24-hour care of the stroke survivor. Additionally, they experience fear and worry about the possibility of stroke recurrence or perhaps even death (Schulz, Tompkins and Rau, 1988; Rombourgh, Howse and Bartfay, 2006). More profound may also be the grief associated with the changed relationship with the stroke survivor (Saban et al., 2010). This loss may be particularly evident in the spouses of stroke survivors. Caregiving has also been linked to general ill-health (Han and Haley, 1999), cardiovascular disease (Lee et al., 2003) and increased mortality (Schulz and Beach, 1999) in the family caregivers who support stroke survivors.

The focus of stroke as a major cause of morbidity and the recognition of the vital role played by family caregivers has resulted in increased research efforts focusing on caregiving following stroke. As a result, there have been publications of literature reviews (Han and Haley, 1999; Low, Payne and Roderick, 1999; Morrison, 1999; Murray et al., 2003) and systematic reviews (McKevitt et al., 2004; Greenwood et al., 2008, 2009a) investigating the impact of caregiving on the family caregivers of stroke survivors. From the reviews, various themes emerged, and a diverse range of caregiver outcomes were reported with most studies focusing on negative caregiving experiences and outcomes.

Han and Haley (1999) in their review of 20 studies dating from 1986 - 1998, identified 17 studies that included measures of psychological distress and the most commonly examined condition was depression. They concluded that the available evidence suggested that the family caregivers of stroke survivors have elevated levels of depression both during the acute and chronic phase than comparable non-caregiver populations. Consistent correlations of family caregiver depression included family caregivers with fewer social contacts, caregivers with more physical symptoms, depression of the stroke patient and family caregivers whose stroke patients had more disruptive behaviour. Similarly, in their review of 31 studies covering a similar period, Low, Payne and Roderick (1999) found that most studies focused on caregivers' psychological health and the negative impact of stroke. High levels of perceived strain and psychological morbidity were also reported in most of the studies compared with the general population.

A qualitative literature review was conducted by Murray et al. (2003) to identify the main challenges experienced by stroke survivors and their family caregivers when at home. Twenty-three studies (mostly from the UK) with approximately 500 patients and 180 family caregivers were included in their review. The authors reported similarities between the patients and family caregivers' experiences and problems and therefore presented their findings together. They identified 203 problem areas organised into five domains. Over 25% of the problem areas identified in the studies related to caregivers and caregiving. The largest domain was represented by the social and relationship consequences of caregiving and the emotional consequences of stroke (anxiety and depression) accounting for 80/203 (39%) of all problems found. This was followed by problems concerning service deficiency (58/203; 29%) and included issues relating to social services, health and transfer of care (Murray et al., 2003).

Although the focus of their review was not family caregivers, in their systematic review of stroke studies, McKevitt et al. (2004) reviewed 95 qualitative studies and divided the studies into five areas of acute care, rehabilitation therapies, life after the acute event, community services and family caregivers' experiences and needs. They identified 11 studies that specifically focussed on caregivers and reported their experiences and needs for support. Feeling ill-prepared for the role, lifestyle changes, physical, emotional and financial problems, were summarised as the most commonly reported experiences of the family caregivers of stroke survivors. Additionally, the family caregivers also reported feeling isolated and that their own needs were being neglected. Some of the specific needs of support identified by the family caregivers include information about the long-term implications of stroke and the availability of

community services (Brereton and Nolan, 2000; Denman, 1998; Kerr and Smith, 2001; Simon and Kumar, 2002).

Furthermore, Greenwood et al. (2008, 2009a) conducted two systematic reviews: one for quantitative and the other for qualitative studies solely focusing on stroke family caregivers. In their review of 17 qualitative studies incorporating 272 family caregivers, Greenwood et al. (2009a) found that the common challenges and needs identified involved information about stroke and the likelihood of further strokes, information and training tailored to individual survivors as well as information concerning financial entitlements and local services. Family caregivers' emotional responses to caring were also apparent and included the need for emotional support. They reported distress, feeling trapped and lacking freedom. The family caregivers also emphasised the adjustment required to becoming a caregiver including giving up paid employment and taking on domestic tasks. Other reported challenges included altered relationships as a result of the changes in the stroke survivor's personality and dependency as well as uncertainty about the future (Greenwood et al., 2009a).

In their review of 39 quantitative studies, which aimed to summarise published studies and identify factors associated with various family caregiver outcomes, Greenwood et al. (2008) noted that a range of outcomes have been investigated, but the emotional well-being of family caregivers received more attention and negative family caregiver outcomes dominated. The psychological characteristics of family caregivers and the stroke survivor's disability paired with impairment and dependency appear to have the most significant impact as factors influencing family caregiver outcomes (Greenwood,

2008). A common family caregiver outcome from the studies included caregiver burden.

Caregiver burden

The concept of caregiver burden was first introduced in the early 1960s in an examination of the community care of mentally ill patients. Grad and Sainsbury (1963) described burden as any cost (negative consequences) to the family of which the patient is a member. A few years later, the concept was split into subjective and objective dimensions. Objective burden referred to events and activities associated with negative caregiving experiences that could be observed, whereas subjective burden referred to feelings aroused in caregivers as they fulfilled their caregiving role (Hoening and Hamilton, 1966).

To further clarify the concept, subsequent studies adopted a broader approach, referring caregiver burden to the physical, emotional, social and financial problems that can be experienced by family members providing care to a chronically ill or impaired family member (Zarit, Reever and Bach- Peterson, 1980; Chou, 2000; Carretero et al., 2009). Given the limitations in performing activities of daily living present in most stroke survivors and the unpreparedness of family caregivers in taking up their supporting role, high levels of caregiver burden have been reported in this population (Nir, Greenberger and Bachner, 2009; Bhattacharjee et al., 2012; Jaracz et al., 2015). Research evidence indicates that family caregivers who experience high levels of burden report lower quality of life (McCullagh et al., 2005).

Positive experiences of stroke family caregivers

While the evidence clearly demonstrates that many stroke family caregivers experience various challenges combined with increased vulnerability and burden, the picture is not entirely bleak as some studies refer to the positive outcomes of caregiving. Evidence from other studies suggests that the family caregivers of individuals who have suffered a stroke may also experience positive outcomes (Mackenzie and Greenwood, 2012; Simeone et al., 2016). In their review of qualitative studies, Greenwood et al. (2009a) noted that a few positive experiences and satisfactions were reported in seven out of the 17 studies although most studies were focused on challenges. These include improved relationships between the stroke survivor and their family in general, satisfaction, pride and fulfilment through the caregiving role, the development of spiritual awareness and reappraisal of priorities.

Furthermore, Mackenzie and Greenwood (2012) conducted a systematic review focusing on the positive experiences of caregiving for stroke survivors. They included nine studies in their review (three quantitative and six qualitative studies) with a total of 330 stroke family caregivers. The most common sources of positive experiences noted in the studies included improvements in the stroke survivors' condition. Seeing the recipient looking well cared for and even small amounts of progress or recovery or no deterioration were satisfying and gave a sense of pride to the family caregivers. Other sources of satisfaction included feeling appreciated and needed by the stroke survivor and the community. The positive results of caregiving were described as providing a sense of meaning and purpose to life and reciprocation for past caring, realising what was important in life and making the caregiver a better person.

Strengthened relationships, feelings of love and devotion were also commonly reported. Family caregivers' responses to the caregiving situation such as learning new skills and overcoming difficulties were linked to increased self-esteem and feelings of mastery. Successful coping was associated with the positive aspects of caregiving. It is therefore important to acknowledge that there can be some benefits experienced by stroke family caregivers. To maximise these experiences, however, stroke family caregivers need to be supported in their caregiving role (Greenwood et al., 2009a).

1.5.4 Support and assessments for family caregivers

Identifying and addressing the needs of family caregivers is a priority in the UK. As a result, different legislation on carer assessment (an opportunity to discuss with the local council the type of support or services required by the family caregiver) (Carers UK, 2015) exists in each of the four nations (England, Scotland, Wales and Northern Ireland). In England, historic changes to legislation (The Care Act, 2014), which was first introduced in April 2015, resulted in new rights for family caregivers, providing them with the same legal rights and entitlements as those they care for (Great Britain Parliament, 2014). The Act places a legal duty on local authorities to assess any family caregiver who requests an assessment or who appears to need support regardless of how much care they provide as was previously the case.

In addition, both national and international stroke guidelines acknowledge the vital role that family caregivers play in supporting individuals following stroke (DH, 2007; Cameron et al., 2016; ISWP, 2016; Stroke Foundation Australia (SFA), 2017). These

guidelines recommend that the family caregivers of stroke survivors should have an assessment of their needs and be referred to appropriate support services to promote optimal outcomes. They further recognise that the needs of stroke survivors and family caregivers may change over time and that they may require regular re-assessment. Nonetheless, minimal guidance is provided in the guidelines about who should carry out the assessments and what they should contain.

Some authors have argued that although most stroke guidelines recommend that family caregivers are supported in their caregiving role, the focus in the guidelines is primarily upon the care of the stroke survivor and not on the family caregivers themselves (Van Heughten et al., 2006). Using the Delphi technique with a panel of experts, Van Heughten et al. (2006) agreed upon 13 areas and 29 guidelines that form the basis of a comprehensive set of caregiver guidelines. They are the only published guidelines available for stroke family caregivers to date. Notable aspects of these recommendations include the early assessment of family caregivers at risk, the formal assessment of caregiver strain and burden and regular monitoring of stroke family caregivers after discharge and long-term assessment and support (Van Heugten et al., 2006).

In practice, the support given to family caregivers is not standard and carer assessments are not universally applied. Economic restraints and austerity measures have resulted in service cutbacks, indicating that the additional resources necessary to carry out these lengthy assessments have not been forthcoming (Carers UK, 2017). Although some local authorities will carry out their own assessments, others outsource

assessments to charitable organisations that support family caregivers resulting in inconsistencies in how these assessments are conducted. In a national survey conducted in the UK with approximately 7,000 respondents, over 20% of family caregivers reported that they did not receive an assessment in the previous 12 months (Carers UK, 2018). Furthermore, delays of longer than six months were reported in about 22% of family caregivers who received an assessment. Some family caregivers in that survey stated that the assessment of their needs had been completed at the same time as the needs of the person that they cared for due to time and resource constraints, and that their needs had not been considered independently or directly (Carers UK, 2018).

Similarly, a national review of services for stroke survivors and their family caregivers conducted by the Care Quality Commission (CQC) (2011) revealed that around two-thirds of stroke survivors whose records were examined as part of this national review had a family caregiver; however, only half of these family caregivers had been offered an assessment and only 44 percent were receiving some support (CQC, 2011). It is therefore apparent that current assessment approaches are ineffective, and therefore, proactive approaches to assessment are needed. Short screening tools are needed to prioritise family caregivers with the highest level of needs or burden to undergo a comprehensive assessment (Knighting et al., 2015, 2016). Furthermore, the screening tools may assist both staff and volunteers who have contact with family caregivers to identify their needs and signpost to them to relevant services before reaching a crisis point.

In the context of stroke care, the above-mentioned shortfalls with assessments are important and have implications for practice. Firstly, advances in stroke treatment such as the decompressive hemicraniectomy discussed earlier in this chapter, indicate that more people will survive stroke and return home (Vahedi et al., 2007; ISWP, 2016). Additionally, rehabilitation models, such as ESD, have led to more stroke survivors being discharged from hospital earlier than ever before (ISWP, 2016). It is therefore important that corresponding strategies are developed to identify and support family caregivers who are called upon to care for the recovering stroke survivors.

Providing good support for stroke family caregivers enables them to cope and assist stroke survivors to preserve their rehabilitation gains (McCullagh et al., 2005; ISWP, 2012). High levels of caregiver burden might exacerbate the patients' depressive symptoms and quality of life and may also predict poor response to rehabilitation (Jaracz et al., 2012; Kamel, Bond and Froelicher, 2012; Han et al., 2017). Furthermore, if the family caregivers' needs are not addressed, this may impede their ability to effectively support the stroke survivor, resulting in a breakdown of care and the subsequent early institutionalisation of the stroke survivor (Lutz et al., 2010; McLennon, Haberman and Davis, 2010). The negative impact of caregiving may also contribute to elder abuse (Beach et al., 2005; Gupta and Chaudhuri, 2008; Lafferty et al., 2016), therefore, there is an urgent need to improve the approaches used to identify the needs and the support offered to stroke family caregivers. Comprehensive, easy-to-use assessment tools are required to identify family caregivers at risk of increasing burden to prevent exposing both stroke survivors and their family caregivers to a higher risk of declining health and well-being (Van Heugten et al.,

2006).

1.6 Chapter summary

This initial chapter aimed to provide an introduction and background to the thesis and formulate a rationale for this study. As evidenced in this chapter, stroke is a devastating illness that causes long-term disability impacting on the lives of both survivors and their family caregivers. The sudden onset of stroke makes it particularly difficult for survivors and their family caregivers to adjust to the significant changes in their lives. The chapter also highlighted recent advances in the treatment and management of stroke, which have created opportunities for stroke survivors but at the same time created some challenges for their family caregivers. It is evident from this chapter that current support mechanisms through carer assessment are insufficient. There is a need for further research to identify other means of identifying the needs of family caregivers and offering timely support. This study therefore aimed to adapt the CAT, a short triage tool which was developed in the context of end- of-life care to develop the CAT-S, specifically for use with the family caregivers of stroke survivors. The following chapter is the first of two narrative reviews which sought to identify the main challenges experienced by the family caregivers of stroke survivors to inform the items for inclusion in the CAT-S.

Chapter 2: Literature review of the challenges experienced by family caregivers who support stroke survivors

2.1 Introduction

The previous chapter (Chapter 1) provided background information about stroke and described the relevant legislation and support services available to family caregivers in the UK. This chapter is the first of two narrative literature reviews, which were conducted as part of this study. The first section of this chapter provides a rationale for the type of literature review conducted. This is followed by a description of the search strategy adopted. Finally, the findings from the review of the studies that have explored the challenges experienced by family caregivers when supporting individuals following the incidence of stroke will be presented.

2.2 Type of review

The purpose of conducting a literature review is to provide an understanding of existing literature and highlight significant gaps in the current knowledge (Jones, 2013; Gray, 2014). A narrative approach to the literature review was therefore undertaken to provide an overview of the research regarding the challenges experienced by stroke family caregivers (Bryman, 2016). Systematic reviews are considered superior to narrative reviews due to the use of explicit and definite methods, yet their narrow focus on an issue may be viewed as restrictive since this inhibits a comprehensive coverage of the issue under study (Collins and Frauser, 2005; Ferrari, 2015). Nonetheless, narrative reviews enable a comprehensive coverage of a wide range of issues within a given a topic hence improving the understanding of the phenomena under study

(Collins and Fauser, 2005; Dijkers, 2009). Furthermore, a narrative review offers unique advantages including a flexible approach allowing the integration of both qualitative and quantitative evidence (Mays, Pope and Popay, 2005; Seah, Tan and Wang, 2015). The utilisation of the descriptive phrases and metaphors used by the participants is permitted in narrative reviews and thus deepens the understanding of the findings. However, narrative reviews have been criticised for being biased by the authors' perspective. To counter this bias, systematic, explicit and transparent approaches to identifying, evaluating and synthesising the relevant literature are therefore required (Booth, Papaioannou and Sutton, 2016). As stated previously, two narrative reviews were conducted as part of this study. The next section will explain the processes that were followed during the first of the two narrative reviews.

2.3 Aim of the literature review

The aim of the first narrative review was to identify research studies that have investigated and reported the challenges experienced by family caregivers who support stroke survivors. This was done to inform the first phase of this study and assist with the development of an interview schedule. Importantly, reviewing existing literature provided an understanding of the key items to be included in the CAT-S (Streiner, Norman and Cairney, 2015).

2.4 Review question

What are the challenges that are experienced by the family caregivers of stroke survivors?

2.5 Search strategy

To aid the literature search, a PEO (population, exposure, outcome) framework (Khan et al., 2003) was devised (Table 2). Defining the scope for any type of literature review is important as it enables researchers to identify the key concepts of the question and consequently the key search terms to be used (Booth, Papaioannou and Sutton, 2016).

Table 2: PEO framework

Population	Family caregivers of stroke survivors
Exposure	Supporting/caring for individuals following stroke
Outcome	Challenges, experiences, concerns

2.6 Search method

The following five electronic databases were searched: CINAHL, MEDLINE, AMED, BNI and PsycINFO. These databases were selected because they contain topics of interest to this review. The key terms used were stroke, caregiver and challenges. Synonyms and related terms were considered and searched using the Boolean 'OR' (e.g. stroke OR 'cerebrovascular accident'). Truncation (*) was utilised to capture spelling variants (e.g. care* would capture 'carer' and 'caregivers'). The different concepts were combined with the use of the Boolean 'AND'. The filter function was used to limit the articles to those published in English and in peer-reviewed journals between the years 2000 and 2016. The decision to only include studies published from the year 2000 onwards was because much progress has been made in the medical

management and rehabilitation of stroke patients since the new millennium. For instance, traditionally, the care of individuals following stroke was provided within general medicine or care for the elderly hospital wards (SUTC, 2007). However, a meta-analysis of the available evidence by the Stroke Unit Trialist Collaboration (SUTC), which is part of the Cochrane Collaboration, concluded that organised inpatient (stroke unit) care is effective in reducing mortality and disability among survivors (SUTC, 1997). As a result, more individuals are admitted and treated within geographically defined stroke units by specialist multidisciplinary stroke teams (NICE, 2008; ISWP, 2016). This has subsequently reduced the length of hospital stay for most stroke survivors (NAO, 2010). Furthermore, accelerated discharge models for stroke survivors, such as early supported discharge (ESD), have resulted in stroke survivors being discharged from hospital earlier than ever before (Fearon et al., 2012; ISWP, 2016). It can therefore be argued that the experiences of family caregivers and the challenges that they experience could also have changed over time. The inclusion of studies published after the year 2000 allowed a focus on studies that reflect the current experiences of stroke family caregivers. Please see Appendix 2 for a full search history. Additionally, hand- searching of the reference lists of the selected studies was undertaken (Booth, Papaioannou and Sutton, 2016).

2.7 Inclusion and exclusion criteria

In accordance with the target population of this study, the age of the family caregivers was limited to 18 years and above. Additionally, studies that included non-stroke family caregivers in their sample were excluded. Furthermore, only family caregivers who were supporting a stroke survivor residing at home as opposed to stroke survivors in

institutionalised settings, such as a nursing home or hospital ward, were included. All study designs along with both qualitative and quantitative methodologies were included. Studies focusing solely on the positive experiences of caregiving were excluded as the aim of the review was to identify items to be included in the CAT-S. Finally, articles focusing on a single aspect of care, such as information needs, were omitted as the aim of the review was to identify the needs and challenges experienced by stroke family caregivers in various aspects of the caregiving role. Table 3 provides a summary of the inclusion and exclusion criteria that were applied to the identified studies to ensure their relevance to the aim of this review.

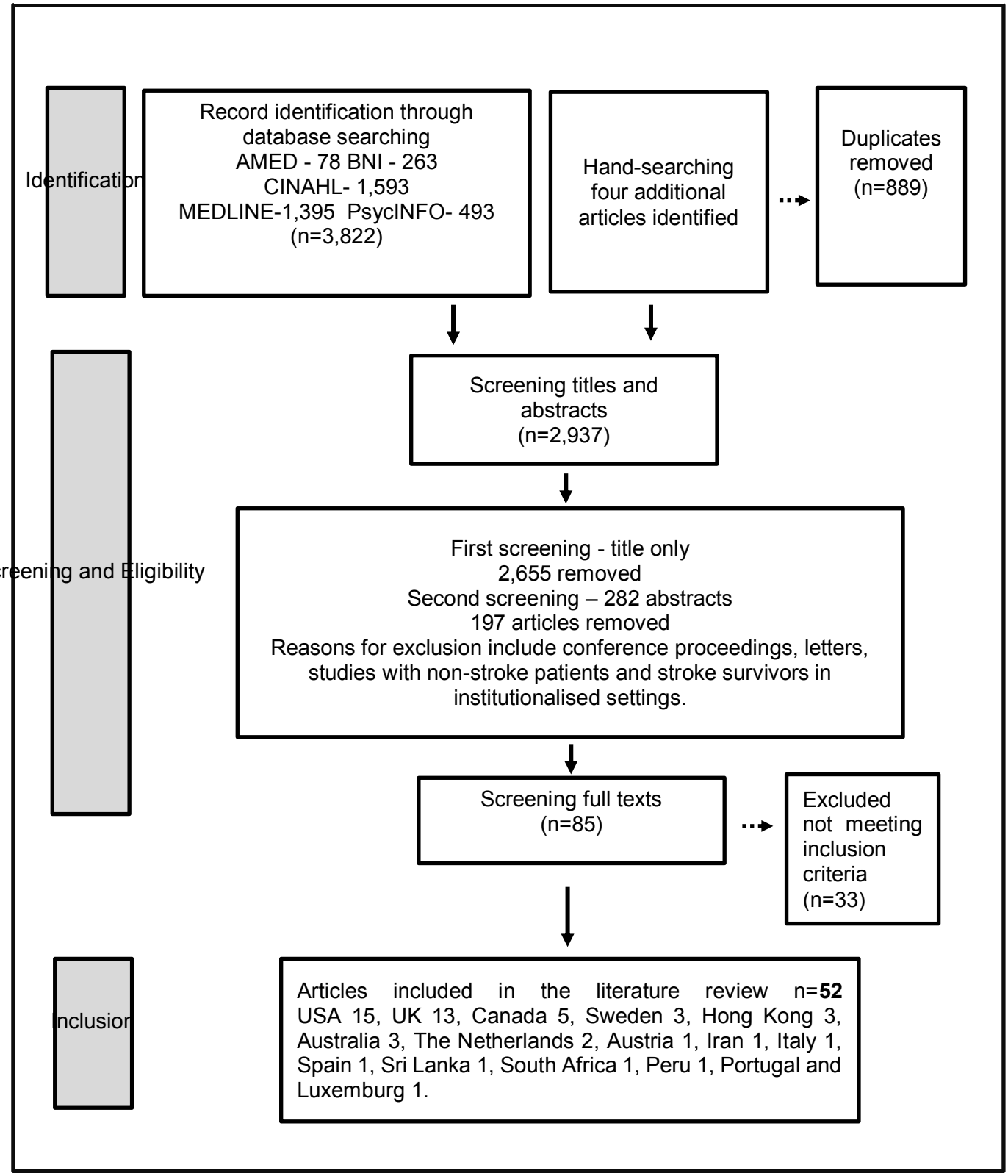
Table 3: Inclusion and exclusion criteria of the selected studies

Inclusion criteria	Exclusion criteria
Family caregivers of stroke survivors living at home, caregivers aged 18 years and above.	Family caregivers of hospitalised stroke patients or those in institutionalised settings, e.g. residential or nursing home; studies with a mixture of stroke and non-stroke caregivers in their sample as well as paid caregivers.
Studies with the primary aim of exploring the challenges, needs or negative experiences of stroke family caregivers.	Studies focusing on single aspects of care such as information needs, rehabilitation, evaluation of a service or an intervention. Studies focusing solely on the positive experiences of caregiving.
Studies with a clear methodology (any design).	Articles without an explicitly stated methodology (literature reviews, non-peer reviewed articles, letters).
Articles published in English between 2000 -2018.	Articles published prior to the year 2000 and not available in English.

2.8 Search results

A summary of the search results is provided in Figure 2. The search yielded 3,822 articles with 889 duplicates, which were excluded at the outset. The hand-searching of journals and reference lists yielded four articles that met the inclusion criteria. The process of selecting and screening studies advocated by Booth, Sutton and Papaioannou (2016) was followed. Firstly, the titles of the articles were examined, and 2,655 articles were excluded resulting in 282 articles. A screening process of the abstracts of the remaining 282 articles was undertaken and 197 articles were removed. The main reasons for exclusion were that the articles were not relevant to the topic under review. The full texts of the remaining 85 articles were obtained, and further scrutiny resulted in 52 articles that met the inclusion criteria. The main reasons for exclusion at this stage were because the sample included young caregivers under the age of 18, studies referencing the family caregivers of hospitalised or stroke survivors in institutions, conference proceedings and a mixture of caregivers supporting patients with other conditions. Literature reviews, commentaries and letters were also omitted. Any studies where the research student was unsure if the inclusion criteria was met, were discussed with the supervisory team and a joint decision made to include or exclude the article.

Figure 2: Summary of search results



2.8.1 Description of identified studies

As illustrated in Figure 2, the studies were conducted in 16 countries with the majority being western developed countries (North America and Europe). Three originated from developing countries in Asia and one study was selected from South Africa and South America, in each case. In one study, the data collection was conducted in two countries (Portugal and Luxemburg) (Lurbe- Puerto, Leandro and Bauman, 2012). A summary of the studies and their location is provided in Appendices 3 and 4. The inclusion of international studies from various parts of the world allowed a breadth of understanding of the caregiving experiences. All the family caregivers in the identified studies were supporting stroke survivors in non-institutionalised settings. The exception is a study from the UK (Katbamna et al., 2017), where one out of the 18 family caregivers who participated in this study was supporting a stroke survivor residing in a residential home. The decision to include this article is based on the relevance of that study's findings to the local context of this study. Furthermore, there is a paucity of research investigating the experiences of Black and Asian caregivers in the UK (Greenwood, 2009a). Therefore, it was deemed appropriate to include this study as it would provide valuable information regarding the experiences of family caregivers of Anglo-Indian origin supporting stroke survivors in the UK.

Out of the 52 selected articles, 37 employed a qualitative research methodology (36 were primary studies and a systematic review of the qualitative studies by Greenwood et al. (2009a) whilst 15 were quantitative studies. A study by King and Semik (2006) was a mixed methods study, however, only the qualitative aspect of the study was included as there was very minimal information in the quantitative arm of the study

relevant to the aim of the review. The selected studies were mainly published between 2009 and 2010 (Table 4).

The ethnicity of the caregivers was reported in less than half of the qualitative studies (n=17) (Subgranon and Lund, 2000; Bakas et al., 2002; Lee, 2004; King and Semik, 2006; Pierce et al., 2007; Buschenfiled, Morris and Lockwood, 2009; Greenwood et al., 2009b; Lin, 2010; Strudwick and Morris, 2010; Saban and Hogan, 2012; Danzyl et al., 2013; El Masry, Mullan and Hackett, 2013; Van Dongen, Josephsson and Ekstam, 2014; Yeung et al., 2015; Katbamna et al., 2017; Torregosa, Sada and Perez, 2018; Wagachchige et al., 2018). Over half of the quantitative studies (n=8) reported the ethnicity of their participants (Grant et al., 2006; Mackenzie et al., 2007; Simon, Kumar and Kendrick, 2008; Haley et al., 2009; Rittman, Hinojosa and Findley, 2009; Perry and Middleton, 2011; Smith-Johnson et al., 2015). Some authors have argued that since caring for stroke survivors normally takes place in family situations, it is important to know the ethnicity of the family caregivers as their experiences may be affected by social, ethnic and cultural differences (Greenwood et al., 2009a). The ethnic groups reported in the selected studies include: White British, White Australian, African American, Chinese, Thai, British of Indian origin, Black, Black American, Latino and Anglo-Australian among others.

Table 4: Research methodology utilised in the reviewed studies

Qualitative studies (n=37)	Quantitative studies (n=15)
Backstrom and Sundin, 2009; Backstrom and Sundin, 2010; Bakas et al., 2002 Bastawrous et al., 2015; Brereton and Nolan, 2000; Bulley et al., 2010; Buschenfield, Morris and Lockwood, 2009; Cameron et al., 2013; Cecil et al., 2011; Chow and Tiwari, 2014; Coombs, 2007; Danzyl et al., 2013; El Masry, Mullan and Hackett, 2013; Gholamzadeh et al., 2015; Gosman-Hedstrom and Dahlin-Ivanoff, 2012; Greenwood et al., 2009a; Greenwood et al., 2009b; Katbamna et al., 2017; Kerr and Smith, 2001; King and Semik, 2006; Lee, 2004; Lin, 2010; Lopez-Espuela et al., 2018; Masuku, Mophosho and Tshabalala, 2018; Moore et al., 2002; Pesantes et al., 2017; Pierce et al., 2007; Saban and Hogan, 2012; Secrest, 2000; Simeone et al., 2016; Smith et al., 2004; Strudwick and Morris, 2010; Subgranon and Lund, 2000; Torregosa, Sada and Perez, 2018; Van Dongen, Josephsson and Ekstam, 2014; Wagachchige, Samarasinghe and Elgan, 2018; Yeung et al., 2015.	Draper and Brocklehurst, 2007; Grant et al., 2006; Haley et al., 2009; Lurbe-Puerto, Leandro and Bauman, 2012; Mackenzie et al., 2007; Perry and Middleton, 2011; Rittman, Hinojosa and Findley, 2009; Simon, Kumar and Kendrick, 2008; Singh and Cameron, 2005; Ski and O'Connell, 2007; Smith-Johnson et al., 2015; Steiner et al., 2008; Tang et al., 2011; Visser-Miely et al., 2008; Visser- Miely et al., 2009.

2.8.2 Overview of qualitative studies

The participants in most studies were the spouses of the stroke survivor, but the samples also included adult children, parents and other relatives. Two studies, one

from Canada (Bastawrous et al., 2015) and the other from Iran (Gholamzadeh et al., 2015), included only adult daughters or daughters-in-law in their studies. The majority of the study participants were female. The number of participants in the studies ranged from three (Van Dongen, Josephsson and Ekstam, 2014) to 93 (King and Semik, 2006). It is important to note that the study by King and Semik (2006) was a mixed methods study. However, a Scottish qualitative study by Smith et al. (2004), interestingly, included a large number of family caregivers (n=90). Nonetheless, the authors reported that their study was part of a larger funded study, which may possibly explain the large numbers of participants recruited. The systematic review by Greenwood et al. (2009a) was retained because it was considered to be comprehensive and directly related to the aim of this review. The systematic review includes articles published between 1996 and 2006. Additionally, seven out of the seventeen articles contained within in the systematic review were identified during the literature search and are included in this narrative review.

The most common data collection method among the 37 studies was that of face-to-face semi-structured interviews. In three studies (Bakas, et al., 2002; Moore et al., 2002; Pierce et al., 2007), semi-structured telephone interviews were carried out. Five studies utilised focus groups to collect their data (Cecil et al., 2011; Gosman-Hedstrom and Dahlin-Ivanoff, 2012; Chow and Tiwari, 2014; Gholamzadeh et al., 2015; Torregosa, Sada and Perez, 2018). In a study conducted by Saban and Hogan (2012) in the USA, written questionnaires containing open-ended questions were used to collect data.

Most studies only included family caregivers in their sample, however, four studies (Danzyl et al., 2013; El Masry et al., 2013; Yeung et al., 2015; Torregosa, Sada and Perez, 2018) investigated the experiences of both the stroke survivors and their family caregivers. In a study by Cameron et al. (2013), the authors reported the experiences of 24 family caregivers and 14 health and social care professionals. Nonetheless, only the experiences of the caregivers were extracted from the articles and included in this literature review. Similarly, studies that reported the experiences of family caregivers prior to hospital discharge (King and Semik, 2006; Greenwood et al., 2009b; Cameron et al., 2013), only data pertaining to the post-discharge period have been included. Two articles included in the literature review were from a longitudinal study by Backstrom et al. (2009; 2010) with findings reported at six months and one year, respectively.

2.8.3 Overview of quantitative studies

Likewise, most of the participants in the 15 quantitative studies were female and the spouses of the stroke survivor. The exception is the study conducted in Australia by Ski and O'Connell (2007) where although the majority of the participants were spouses (10 out of 13), a slightly higher number of males participated in the research compared to females (n=7 versus n=6). The number of participants in the studies ranged from 13 (Ski and O'Connell, 2007) to 276 family caregivers in a study that was conducted by Rittman, Hinojosa and Findley (2009) in the USA. The most common method of data collection was to conduct structured face-to-face interviews. This is followed by structured telephone interviews, which were conducted in four studies (Perry and Middleton, 2001; Steiner et al., 2008; Haley et al., 2009; Rittman, Hinojosa and

Findley, 2009). In a Canadian study by Sing and Camron (2005), the researchers utilised both telephone and face-to-face structured interviews. A study conducted by Smith-Johnson et al. (2015) did not specify the methods utilised to collect data.

Most studies solely comprised family caregivers, yet three studies involved stroke survivor and caregiver dyads (Draper and Brocklehurst, 2007; Perry and Middleton, 2011; Lurbe-Puerto, Leandro and Bauman, 2012). In these studies, only the experiences of the caregivers were included in the review. Seven studies were cross-sectional, whereas the remaining eight were longitudinal studies (Grant et al., 2006; Mackenzie et al., 2007; Ski and O'Connell, 2007; Simon, Kumar and Kendrick, 2008; Steiner et al., 2008; Visser-Miely et al., 2008; Visser- Miely et al., 2009; Perry and Middleton, 2011). In the longitudinal studies that involved the pre-discharge period, only data pertaining to the period following hospital discharge were included in the review.

2.9 Data extraction and quality appraisal

In line with the requirements for narrative literature reviews, data extraction tables were created (Booth, Papaioannou and Sutton, 2016). Two tables were formulated: one for qualitative studies and the other for quantitative studies. The key descriptive details of each study were recorded in the data extraction table depending on the study methodology. This included: the author, date of publication, country where the study was conducted, study design or methods of data collection and key findings. The studies in each table are presented in alphabetical order based on the authors' surnames. See Appendix 3 for qualitative studies and Appendix 4 for quantitative studies.

Additionally, all the selected articles (n=52) were critically appraised to assess methodological quality (Fink, 2014; Booth Sutton and Papaioannou, 2016). Currently, there is no definitive approach in the critical appraisal and integration of findings from studies with varied methodological approaches (Walshe et al., 2009). Therefore, the selected studies were critically appraised for methodological quality using various critical appraisal tools depending on the study design and methodology.

The Critical Appraisal Tools developed by the Critical Appraisal Skills Programme (CASP) (2018) were utilised to appraise and assess the methodological quality of the qualitative studies. The CASP tools were preferred because they are easy to use and have a straightforward method of employing ten questions to systematically explore the issues of rigour, credibility and relevance of the studies (Akobeng, 2005; Williams and Murray, 2013). The CASP checklists have also been widely used in the stroke literature (Kristensen et al., 2011; Santik et al., 2013; Williams and Murray, 2013; Quinn, Murray and Malone, 2014). Two CASP checklists were used to appraise the literature: one for systematic reviews (10 items) and the other for qualitative studies (10 items) for the 36 qualitative studies.

The CASP checklists, were however, developed as 'pedagogic educational tools' to be used in a workshop setting and therefore do not include a facility to score the quality of the articles (CASP, 2018). To aid the quality appraisal of the articles, it was deemed appropriate to adapt the checklists and create a numerical indicator of quality for all the reviewed studies. Each question on the two checklists was awarded a score of two if it was adequately addressed; a score of one if it was partially addressed and zero if

the question was not addressed (Zhao, Brettle and Qui, 2018). Additional scores of not clear (NC) and not applicable (N/A) were applied to differentiate between adequately addressed and not partially addressed. This resulted in five scoring options: 2, 1, 0, NC and N/A. The studies could achieve a maximum score of 20, indicating a high number of quality elements reported in the articles or a minimum score of zero.

For quantitative studies, the Joanna Briggs Institute (JBI) Critical Appraisal Tools (JBI) were preferred as they provided a wider checklist for quantitative studies of various designs (JBI, 2017). Furthermore, they are widely used in the UK. Two JBI checklists were therefore utilised to appraise the methodological quality of the studies: the JBI checklists for analytical cross-sectional studies (8 items) and one JBI checklist for cohort studies (11 items). Likewise, the JBI checklists do not include a scoring facility to rate the quality of the studies (JBI, 2017). Therefore, like the CASP checklists, the JBI checklists were also adapted, and a numerical indicator of quality created. The same scoring system utilised for the CASP tools was utilised to appraise the quality of the quantitative studies. Each question on the JBI checklists was awarded (2) for a 'yes', partially addressed (1), 'no' (0), 'unclear' (NC) and 'Not Applicable' (N/A).

None of the studies was excluded based on quality ratings (Booth, Papaioannou and Sutton, 2016). Higher scores indicated a higher number of quality elements recorded by the authors. All the studies provided clear research aims and the choice of research design was appropriate for answering the research question. Additionally, each study provided valuable information to aid the understanding of the challenges experienced

by the family caregivers who support stroke survivors. In studies where the scores were lower, this was because the authors provided insufficient details regarding the recruitment strategy. For qualitative studies, reflexivity and how ethical standards were maintained during the conduct of the study were the areas that were least reported in detail.

2.10 Identified themes

The findings from the studies were thematically analysed, and seven inter- related themes were identified from the literature. Each of the identified themes is based on findings from several studies, thus providing a degree of triangulation (Lou et al., 2017b). The themes include: training and information needs, emotional responses to caregiving, physical health problems, respite support, financial and employment issues, challenges with social support and formal support, and coping strategies. Each theme will be discussed in turn.

2.10.1 Training and information needs

Twenty-three studies contributed to the development of the theme regarding the training and information needs of stroke family caregivers (Brereton and Nolan, 2000; Kerr and Smith, 2001; Bakas et al., 2002; Smith et al., 2004; Mackenzie et al., 2007; Ski and O'Connell, 2007; Greenwood et al., 2009a; Bulley et al., 2010; Lin, 2010; Cecil et al., 2011; Perry and Middleton, 2011; Saban and Hogan, 2012; Cameron et al., 2013; Danzyl et al., 2013; El Masry, Mullan and Hackett, 2013; Chow and Tiwari, 2014; Gholamzadeh et al., 2015; Smith-Johnson et al., 2015; Simeon et al., 2016; Katbamna et al., 2017; Pesantes et al., 2017; Lopez-Espuela et al., 2018; Masuku, Mophosho

and Tshabalala, 2018; Wagachchige, Samarasinghe and Elgan, 2018). A wide range of training and information needs were reported by the family caregivers. Predominantly, the needs were in relation to how to provide support to the stroke survivor with activities such as medications, managing finances, moving and handling and information regarding the local support services available to caregivers.

A systematic review considered to be of high quality (CASP score, 17) was conducted by Greenwood et al. (2009a). Articles were sourced from seven databases. A total of 17 qualitative articles (USA, n=9; UK, n=4; Australia, n=2; Thailand, n=1 and Hong Kong, n=1) were included in the review. The most common challenges and needs reported by the participants in the studies were information and training needs. The information needs encompassed general information about stroke, particularly how to prevent further strokes and information and training needs tailored to the individual needs of the stroke survivor. Additionally, information regarding financial entitlements, as well as local support services for the caregivers were also mentioned by the participants. However, a limitation of the systematic review by Greenwood et al. (2009a) is that the authors did not perform any hand-searching or search the grey literature. Therefore, it is possible that other important studies were omitted in this review. Nonetheless, despite this limitation, the authors highlighted important challenges that are experienced by the family caregivers who support stroke survivors.

The training needs to provide physical aspects of care were stated in eight studies (Brereton and Nolan, 2000; Kerr and Smith, 2001; Bakas et al., 2002; Smith et al., 2004; Cecil et al., 2011; Saban and Hogan, 2012; Gholamzadeh et al., 2015;

Katbamna et al., 2017). In a qualitative study conducted with family caregivers of White and Anglo-Indian origin in the UK (n=18) (Katbamna et al., 2017) (CASP score 14), the participants reported lacking the appropriate skills and competence to provide care to the stroke survivors, regardless of their ethnicity. The tasks considered most difficult for family caregivers were those involving lifting and handling, continence management and feeding. Participants described feeling ill-equipped and poorly prepared to provide the level of care that was required. Most family caregivers found the process of providing care stressful and exhausting. At the follow-up interviews which were conducted six months following the stroke, some participants claimed that neither their responsibilities nor stress levels had improved despite the stroke survivor's improved abilities. However, the focus of this study was the period up to six months post-stroke and is therefore unlikely to be representative of, or generalisable, to all stroke family caregivers, particularly those providing care beyond six months following stroke. Similarly, a quantitative study that was conducted in Iran with 17 family caregivers (Gholamzadeh et al., 2015) (CASP score 17) identified managing the patient's activities of daily living and the patient's moving and handling as the most frequent and predominant educational needs. Data collection was conducted at one month post-hospital discharge for all participants and may therefore not be transferable to family caregivers providing support to stroke survivors beyond this period.

In contrast, the participants in four studies emphasised the challenges that they experienced with managing the emotional and behavioural changes of the stroke survivors (Mackenzie et al., 2007; Pierce et al., 2007; Bulley et al., 2010; Masuku,

Mophosho and Tshabalala, 2018). In a UK study with nine spousal caregivers (Bulley et al., 2010) (CASP score, 18), the participants highlighted lacking the necessary skills to manage the emotional and behavioural changes exhibited by the stroke survivor. Aggression was reported as the most problematic behaviour by the family caregivers that triggered anxiety and stress. The family caregivers appeared to blame healthcare professionals for focusing on the physical aspects of care and neglecting the emotional and behavioural changes in their spouses. Other difficult behaviours and emotions reported by the caregivers were confusion and depression (Pierce et al., 2007), personality changes and speech problems (Masuku, Mophosho and Tshabalala, 2018).

In some studies, the participants highlighted the lack of information on the local support services available to caregivers (Lin, 2010; Cameron et al., 2013; Danzyl et al., 2013; Simeone et al., 2016; Wagachchige, Samarasinghe and Elgan, 2018). Family caregivers reported having to navigate the systems alone resulting in exhaustion and delays in seeking timely support. Equally, a quantitative study in Australia with 32 family caregivers reported lower satisfaction scores at one month and three months post-hospital discharge on the Carer Satisfaction Scale (CSS) ($r_s = 0.409$, $p<0.001$). The highest overall levels of dissatisfaction rated by family caregivers originated from non-receipt of information (Perry and Middleton, 2011). To overcome challenges regarding information provision, the participants in some studies proposed the need for a contact person within the healthcare systems to respond to their questions (Kerr and Smith, 2001; Backstrom and Sundin, 2009; Saban and Hogan, 2012; Danzyl et al., 2013) or a network of healthcare professionals they could call for advice (Bakas et

al., 2002). Family caregivers in a qualitative study in Spain (Lopez-Espuela et al., 2018) (CASP score 17) reported wanting more information regarding how to help the stroke survivor to do therapeutic exercises at home to maximise recovery. Problem-solving skills were identified as education needs in two studies (Cameron et al., 2013; Gholamzadeh et al., 2015). It was evident from the studies that the family caregivers training and information needs vary widely and therefore need to be tailored.

2.10.2 Emotional responses to caregiving

Overwhelmingly, emotional struggles were emphasised in almost all the qualitative studies and 12 quantitative studies. The sudden nature of stroke makes it particularly difficult for this group of family caregivers to adjust to their role. Subsequently, high levels of stress-related psychological problems have been previously reported among stroke family caregivers (Stroke Association, 2013).

Anxiety and depression were reported in a third of the studies (Subgranon and Lund, 2000; Bakas, 2002; Lee, 2004; Smith et al., 2004; Singh and Cameron, 2005; Grant et al., 2006; Draper and Brocklehurst, 2007; Visser-Miely et al., 2008; Haley et al., 2009; Rittman, Hinojosa and Findley, 2009; Visser-Miely et al., 2009; Bulley et al., 2010; Lin, 2010; Tang et al., 2011; Danzyl et al., 2013; El Masry, Mullan and Hackett, 2013; Chow and Tiwari, 2014; Gholamzadeh et al., 2015; Masuku, Mophosho and Tshabalala, 2018). The associated causes for anxiety and depression included exhaustion, caregiving role overload, giving up employment to provide care, financial struggles, sense of loneliness and lack of support from family members among others. The lack of appreciation from the stroke survivor and professionals, despite the family

caregivers' enormous contributions to providing care, appeared to be the trigger for depression in most caregivers, as per the findings of a qualitative study by Chow and Tiwari (2014) (CASP score 14) in Hong Kong with 29 family caregivers.

A quantitative study with 44 couples in the UK (JBI score, 14) (Draper and Brocklehurst, 2007) noted high scores on the General Health Questionnaire (GHQ-12) among the spousal caregivers ranging from 4 to 30 with a mean value of 15.1 (SD = 5.93). The authors compared their findings with a reference group of 143 family caregivers supporting a dependent adult with a long-term physical or mental disability obtaining a figure of 14.6 (SD = 7.2) (McCabe et al., 1996). The higher scores observed in the study by Draper and Brocklehurst (2007) indicate a greater degree of psychological distress among the spousal caregivers of stroke survivors. This finding is important considering that most family caregivers of stroke survivors tend to be spouses as revealed from the studies included in this review. Furthermore, an inferential analysis revealed no correlation between the GHQ-12 scores and the Caregiver Strain Index (CGSI) scores of spousal caregivers and the Barthel Index (BI) scores of the stroke survivor (Draper and Brocklehurst, 2007). Over 75% of the spousal caregivers were supporting stroke survivors with a BI score of over 50; the mean BI score was 68. The authors emphasise the importance of health and social care professionals not to assume that the partners of stroke survivors with a slight degree of physical disability are immune to psychological and emotional problems. Nevertheless, the mean length of time since the stroke in this study was 6.9 months (ranging from 6 weeks to 15.5 months) and thus may not be representative of other spousal caregivers providing care beyond this period. A quantitative study in Hong

Kong (Tang et al., 2011) also observed associations between caregivers' depressive symptoms and post-stroke depression in the stroke survivors.

In contrast, Visser-Miely et al. (2009) (JBI score, 17) conducted a quantitative longitudinal study with 119 spousal caregivers in the Netherlands to assess changes in their psychological functioning (burden, depressive symptoms, harmony in relationship between the patient and spouse and social relations) during the first three years following stroke. Data were collected before hospital discharge (T1), approximately two months after discharge (T2), approximately one-year post-discharge (T3) and at three years post-stroke (T4). A consistent decrease in caregiver burden was noted at T2, T3 and T4. These findings are consistent with those reported in a qualitative study conducted by Brereton and Nolan (2000) in the UK, where seven family caregivers were followed over an 18-month period and reported that caregiving became more routine as their competence grew over time and the stroke survivor's functions improved. Nonetheless, Visser-Miely et al. (2009) observed a high percentage of spouses (over 50%) who still reported depressive symptoms at T2, T3 and T4. Furthermore, although depressive symptoms were noted to decrease during the first year after stroke, an increase was observed between one and three years post-stroke (mean GDS scores T2 = 2.6; T3 = 2.4; T4 = 2.5). The authors suggest that the slight but significant increase in depressive symptoms might be related to the consistent decrease in social relationships and harmony in the relationship which were noted between T2 and T4.

Furthermore, some participants in a qualitative study by Bulley et al. (2010) (CASP

score 18), who were providing care between two to seven years post- stroke in the UK, reported that they were taking medications prescribed by their General Practitioner (GP) to manage their depressive symptoms. In contrast, family caregivers in a study conducted in South Africa by Masuku, Mophosho and Tshabalala (2018) (CASP score 17) did not receive any medical support regarding their depressive symptoms. Six out of 14 family caregivers who participated in that study suffered emotional breakdown whilst sharing their experiences and were subsequently referred for counselling. In an American qualitative study by Danzyl et al. (2013) (CASP score 18) with 12 family caregivers, some participants were reluctant to seek help regarding their emotional well-being as this was viewed as a sign of weakness and embarrassment. The findings highlight the prevalence of depressive symptoms among the family caregivers of stroke survivors along the caregiving trajectory. Additionally, the findings suggest the need for a proactive approach by health and social care professionals to identify and support the needs of family caregivers regarding their emotional well-being.

Sadness and grieving the loss of earlier life was a concern for the caregivers in five studies (Bastawrous et al., 2015; Van Dongen, Josephsson and Ekstam, 2014; Lin, 2010; El Masry, Mullan and Hackett, 2013; Gosman- Hedstrom and Dahlin-Ivanoff, 2012). Additionally, family caregivers, particularly those in a marital relationship, reported the loss of intimacy and associated tensions (Coombs, 2007; Backstrom and Sundin, 2009; Lopez- Espuela et al., 2018). In a qualitative study conducted by Coombs (2007) (CASP score 15) in Canada with spousal caregivers (n=8), the participants reported the physical and cognitive deficits of stroke on their spouses,

which resulted in the loss of previous intimate relationships. Often, participants described 'living with a stranger', as they could no longer rely on their partners for support (Coombs, 2007:114). For middle-aged close relatives (under the age of 65), the realisation that life will never be the same in addition to the prospects of living 30 -40 years with their spouse who suffered stroke, evoked feelings of intense sorrow (Backstrom and Sundin, 2010).

It is noteworthy that two studies conducted in Asia (Chow and Tiwari, 2014; Gholamzadeh et al., 2015) and one study from South Africa (Masuku, Mophosho and Tshabalala, 2018) reported emotional stress stemming from the obligatory roles to look after parents (Chow and Tiwari, 2014) and provide care to parents-in-law (Gholamzadeh et al., 2015). The feminisation of caregiving was reported by Masuku, Mophosho and Tshabalala (2018), as due to cultural norms female spouses and adult daughters were expected to automatically provide care to the stroke survivor without much choice. Other emotions highlighted by caregivers include: constant worry and fear that the stroke survivor may have another stroke (Secrest, 2000; Coombs, 2007; Greenwood et al., 2009a; Gosman-Hedstrom and Dahlin-Ivanoff, 2012; Saban and Hogan, 2012), loneliness (Chow and Tiwari, 2014; Ghomzadeh et al., 2015; Katbamna et al., 2017) and guilt (Smith et al., 2004; Wagachchige, Samarasinghe and Elgan, 2018).

2.10.3 Physical health problems

Another theme that was reported in a third of the studies were physical health problems. Participants linked their poor physical health to the strain of caregiving. The

most common symptom reported in 20 studies was physical exhaustion (Subgranon and Lund, 2000; Kerr and Smith, 2001; Bakas et al., 2002; Lee, 2004; Singh and Cameron, 2005; Coombs, 2007; Mackenzie et al., 2007; Simon, Kumar and Kendrick, 2008; Backstrom and Sundin, 2009; Rittman, Hinojosa and Findley, 2009; Backstrom and Sundin, 2010; Perry and Middleton, 2011; Tang et al., 2011; Lurbe-Puerto, Leandro and Bauman, 2012; Danzyl et al., 2013; Gholamzadeh et al., 2015; Simeone et al., 2016; Katbamna et al., 2017; Masuku, Mophosho and Tshabalala, 2018; Wagachchige, Samarasinghe and Elgan, 2018).

Lack of sleep, inadequate rest and skipping meals were reported as factors that contributed to physical exhaustion in a qualitative Sri-Lankan study (CASP score 18) by Wagachchige, Samarasinghe and Elgan (2018). Some caregivers in that study were looking after their own small children together with the stroke survivor and as such reported feeling overburdened. Other physical problems reported by the family caregivers included neck and leg pain and high blood pressure. Seeking medical treatment appeared to be difficult for most caregivers, as they could not leave the stroke survivor alone. This study's findings provide an insight into the reasons that may hinder stroke family caregivers from accessing treatment regarding their physical well-being. Similar findings were reported in another qualitative study conducted with a large number of family caregivers in the UK (n=90; 65 females, 25 males) (Smith et al., 2004). At one year post-stroke, most participants described caregiving as relentless and reported being on call 24 hours a day, seven days a week. The findings are consistent with a quantitative study conducted with 276 family caregivers in America (Rittman, Hinojosa and Findley, 2009), where sleep disturbance was reported

in 80% of the participants.

Back and joint pain were reported in four qualitative studies (Saban and Hogan, 2012; Chow and Tiwari, 2014; Gholamzadeh et al., 2015; Wagachchige, Samarasinghe and Elgan, 2018) where caregivers attributed the physical pain to strenuous physical activities such as lifting when supporting the stroke survivors. In other studies, especially those with elderly participants, providing care exacerbated existing medical conditions such as arthritis (Chow and Tiwari, 2014; Simeone et al., 2016; Katbamna et al., 2017; Masuku, Mophosho and Tshabalala, 2018). In two studies (Moore et al., 2002; Smith et al., 2004), the participants were concerned with their advancing age and deteriorating health and expressed worries regarding their ability to provide care in the future. Fainting and dizziness were other physical symptoms reported by family caregivers (Subgranon and Lund, 2000). It is apparent from the studies that providing support to individuals following stroke may contribute to the poor physical health of their family caregivers. In a quantitative study by Tang et al. (2011) (JBI score 12) in Hong Kong, poor self- rated general health was identified as a significant contributor to the severity of depressive symptoms in family caregivers. This finding is important because, as previously stated in Chapter 1, stroke is common in individuals who are over the age of 65 and are thus more likely to be supported by their spouse within a similar age group who may have multiple pre-morbid conditions impacting on their physical well-being. Nonetheless, in comparison with emotional problems, physical health problems were reported to a lesser extent in the reviewed studies.

2.10.4 Financial and employment issues

Financial and employment issues were also highlighted as challenges by the participants in several studies. Financial hardship was reported by family caregivers in 15 studies (Brereton and Nolan, 2000; Kerr and Smith, 2001; Bakas et al., 2002; Smith et al., 2004; Backstrom and Sundin, 2009; Lurbe- Puerto, Leandro and Bauman, 2012; Saban and Hogan, 2012; El Masry, Mullan and Hackett, 2013; Chow and Tiwari, 2014; Ghomzadeh et al., 2015; Simeone et al., 2016; Katbamna et al., 2017; Pesantes et al., 2017; Masuku, Maphosho and Tshabalala, 2018; Wagachchige, Samarasinghe and Elgan, 2018). The reasons for the financial hardship varied among the participants, but increased expenditure was mentioned by most caregivers. For instance, in one of the earlier qualitative studies conducted with family caregivers (n=7) who had been providing care between two to four years in the UK (Brereton and Nolan, 2000) (CASP score 12), the participants incurred costs related to the equipment or aids required to deal with incontinence. One family caregiver in that study reported the expenses incurred buying new clothes as the stroke survivor gained weight. Family caregivers reported costs arising from additional food, heating, laundry, transportation and obtaining aids to assist with providing care in a qualitative study that was conducted with 18 family caregivers in the UK (Katbamna et al., 2017). In a Swedish qualitative study with nine middle-aged family caregivers (mean age 54; range 40-64) (Backstrom and Sundin, 2009) (CASP score 15), the participants reported financial burdens resulting from major house modifications requiring a substantial amount of money to meet the stroke survivors' disability needs. Increased expenses related to medication and transport were also reported by the participants in that study.

Additionally, in a study by Saban and Hogan (2012) (CASP score 12), which was conducted as part of a mixed methods study with 46 family caregivers in the USA, some participants lost their retirement savings as they had to pay for their medical bills. This is unsurprising as healthcare is not free in the USA in comparison with countries such as the UK where healthcare is mostly free. Equally, caregivers from developing countries with limited public health funding mentioned treatment costs as a key challenge that caused them distress. For instance, in a study by Masuku, Mophosho and Tshabalala (2018) in South Africa, most participants sacrificed rehabilitation visits due to lack of finance. In Hong Kong (Chow and Tiwari, 2014), family caregivers had to pay for wheelchairs and the installation of equipment such as handrails. As a result, they reported spending less on food to cope financially. In most studies, the loss of income of either the caregiver or the stroke survivor also contributed to the financial hardships.

In other developed nations including the UK, family caregivers may seek and qualify for financial support through the government's welfare system (Department for Works and Pension (DWP), 2016). Sadly, in three studies conducted in the UK (Kerr and Smith, 2001; Smith et al., 2004; Katbamna et al., 2017), most participants were unsure about their entitlements. Other family caregivers who have previously accessed the UK financial benefits system have described it as too complex, lengthy and degrading particularly in instances when the family caregivers have to prove their eligibility to the financial entitlement (Smith et al., 2004). Due to the lack of information regarding financial benefits, only a few family caregivers reported being able to access this type of financial support.

Issues related with employment were highlighted in six studies (Bastawrous et al., 2015; Buschenfield, Morris and Lockwood, 2009; Van Dongen, Josephsson and Ekstam, 2014; Lin, 2010; El Masry, Mullan and Hackett, 2013; Simeone et al., 2016). Although most of the participants in the studies were retired, some caregivers combined paid employment and the caregiving role. In an Italian qualitative study by Simeone et al. (2016) (CASP score 18), family caregivers (n=25) described difficulties balancing being a caregiver and coping with employment. Most participants constantly felt that caregiving diverted their energy from their job, whilst others were afraid it was impacting on their performance at work and feared losing their job. Similarly, adult daughters (n=23) in a Canadian study by Bastawrous et al. (2015) reported reducing their working hours whilst other delayed returning to work. Other family caregivers reported giving up employment altogether, thus contributing to their financial strain. Participants who gave up employment to provide care stated that the stroke survivor's uncertain recovery prevented them from committing to employment opportunities.

2.10.5 Respite support

The theme regarding respite support was highlighted in 14 studies. Seven studies originated from the UK (Kerr and Smith, 2001; Smith et al., 2004; Mackenzie et al., 2007; Buschenfield, Morris and Lockwood, 2009; Greenwood et al., 2009b; Bulley et al., 2010; Cecil et al., 2011), four were from the USA (Bakas et al., 2002; Saban and Hogan, 2012; Danzyl et al., 2013; Torregosa, Sada and Perez, 2018) and one from Canada (Cameron et al., 2013), Hong Kong (Lee, 2004) and Sweden (Gosman-Hedstrom and Dahlin- Ivanoff, 2012). Family caregivers reported that they relied on family members and friends for relief to enable them to have a break from caring.

However, this was not always possible, particularly with family caregivers who had relatives residing in a different location.

Family caregivers who were receiving caregiving relief from family members and friends in a Canadian study (CASP score 18) by Bastawrous et al. (2015) reported that the caregiving role was less arduous. Nonetheless, when the family caregivers did not receive this support, they reported feeling overwhelmed and tired. Furthermore, the respondents emphasised the need to get away from the caregiving situation to allow time for themselves and rest. Respite was identified as important support for stroke family caregivers in an American qualitative study (CASP score 18) with 12 participants by Danzyl et al. (2013). Unfortunately, respite services were inaccessible for caregivers residing in the Kentucky state. Lack of respite was also identified as a key stressor by family caregivers in a study by Saban and Hogan (2012) conducted in the USA.

In contrast, respite services were accessible to family caregivers who participated in a qualitative study with eight family caregivers in the USA (Torregosa, Sada and Perez, 2018) (CASP score 17). However, some respondents described feelings of guilt, triggered by accessing respite services. Consequently, the guilty feelings acted as a barrier for the caregivers to access respite services. Likewise, the authors of a Swedish study (Gosman- Hedstrom and Dahlin-Ivanoff, 2012) (CASP score 17) reported that accessing respite services was in some instances dependant on the approval of the stroke survivor. They described that some family caregivers engaged in ongoing negotiations with their partners. Stroke survivors had to agree to either

attend a day rehabilitation unit or stay in a nursing home for a while to enable the caregivers a few hours of free time or a chance to go away for a few days. The findings suggest that health and social care professionals need to understand the barriers that may prevent family caregivers from accessing respite services such as feelings of guilt. However, it is important to note that the caregivers' preferences for respite may vary. For instance, in a qualitative study by Kerr and Smith (2001) (CASP score 12), only a few felt that institutional respite was an option, as most preferred additional support in their home. However, in another qualitative study in the UK (Smith et al., 2004) (CASP score 18), only a few reported having accessed respite. The few who accessed respite reported that a break from caring enabled them to cope, while other family caregivers were concerned about the quality of respite services (Greenwood et al., 2009b; Strudwick and Morris, 2010; Cecil et al., 2011; Cameron et al., 2013).

2.10.6 Challenges with social support and formal support

Personal social support also referred to as social support has been defined as 'the existence or availability of people whom we can rely upon, people who let us know they care about us, value us and love us' (Sarason et al., 1987:127). In the reviewed studies, the participants mostly received social support from friends and family. Those who received this type of support felt privileged and valued it. Furthermore, they remarked that this enabled them to cope with caregiving. However, in seventeen studies, social support was reported as either being minimal or absent (Lee, 2004; Grant et al., 2006; Simon, Kumar and Kendrick, 2008; Visser-Miely et al., 2008; Greenwood et al., 2009a; Visser- Miely et al., 2009; Backstrom and Sundin, 2010; Strudwick and Morris, 2010; Cecil et al., 2011; Lurbe-Puerto, Leandro and Bauman,

2012; Saban and Hogan, 2012; Cameron et al., 2013; Chow and Tiwari, 2014; Gholamzadeh et al., 2015; Smith-Johnson et al., 2015; Katbamna et al., 2017; Masuku, Mophosho and Tshabalala, 2018).

A South African qualitative study (CASP score 17) was conducted by Masuku, Mophosho and Tshabalala (2018) with 14 female family caregivers supporting stroke survivors with aphasia. The respondents highlighted that the lack of social support resulted in feelings of neediness and loneliness which further exacerbated the burden of caregiving. Likewise, in an Australian qualitative study by El Masry, Mullan and Hackett (2013), the participants became disappointed when family or friends were not supportive enough and greatly appreciated pro-active offers of support. Similar disappointments were reported in other studies (Lee et al., 2004; Strudwick and Morris, 2010; Saban and Hogan, 2012). Participants in two studies highlighted the importance of peer support groups to combat loneliness and social isolation among stroke family caregivers (Chow and Tiwari, 2014; Gholamzadeh et al., 2015).

Conversely, Grant et al. (2006), in their quantitative longitudinal study (JBI score 17) with 52 family caregivers in America, observed that high levels of support were associated with lower levels of depressive symptomatology and higher levels of general well-being. On the contrary, a decline in social support was linked with caregiver depression and poor general well-being. Nonetheless, some studies reported the various challenges in terms of accessing social support. For instance, a qualitative study with 15 Chinese family caregivers in Hong Kong (Lee, 2004) (CASP score 11) noted that older participants tended to hide their problems from other family

members. Additionally, the caregivers refused to approach their family and friends for support and did not seek any professional help either. This finding highlights the importance of health and social care professionals understanding the complexities regarding social support such as age and culture. The findings further suggest that the presence of family members may not always result in family caregivers receiving social support. A proactive approach is therefore required to ensure that the needs of family caregivers in such situations are met by health and social care professionals.

Issues regarding formal services and support from health and social care professionals were highlighted in a third of the studies. The experiences of family caregivers concerning formal support services were varied. While some family caregivers identified positive experiences when interacting with formal support services and professionals, others were clearly dissatisfied. In a qualitative study by Strudwick and Morris (2010) (CASP score 16) with nine family caregivers of Afro-Caribbean origin residing in the UK, the participants reported a sense of battling with services to get the required support. Bureaucracy and delays in getting the needed services and equipment were challenges that were reported in an Italian study with 25 family caregivers by Simeone et al. (2016) (CASP score 18). Family caregivers in other studies highlighted the unreliability of the services available to them (Smith et al., 2004; Greenwood et al., 2009b; Danzyl et al., 2013), while others felt that their needs were not adequately assessed (Katbamna et al., 2017). In contrast, the participants from an underserved community in a USA/Mexico border town reported the lack of medical and social services in their area with some planning to take political action by contacting state representatives to request improved access to care for stroke

survivors and their family caregivers (Torregosa, Sada and Perez, 2018) (CASP score 17). The reported challenges appeared to generate additional anxiety and worry among family caregivers.

Additionally, poor communication between family caregivers and professionals was mentioned by the participants. An Irish qualitative study with ten spousal caregivers (Cecil et al., 2011) (CASP score 15) stated that participants in their study lacked the confidence to speak to health professionals on behalf of their husbands. Some even spoke of overcoming their fear of 'making a fuss' if they called for medical help when this was not needed. In other studies, the participants highlighted the lack of attention given to family caregivers' needs by professionals (Bakas et al., 2002; Ghomzadeh et al., 2015). In the same vein, the participants in a UK qualitative study by Brereton and Nolan (2000) complained about the failure of health professionals to draw on family caregivers' knowledge and expertise concerning providing support to the stroke survivor. This created feelings that the family caregivers are 'invisible' to healthcare professionals. The findings highlight the importance of effective communication and positive relationships between family caregivers and healthcare professionals. This may empower family caregivers to seek support when required.

2.10.7 Coping strategies

Another theme identified in the studies is related to coping. Theories regarding coping strategies are primarily based on the work of Lazarus and Folkman (1984), who defined coping as 'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding

the resources of the person' (Lazarus and Folkman, 1984:141). Although coping was not the primary focus in most of the reviewed studies and of this narrative literature review, nineteen articles contributed to the development of this theme. Six studies originated from the UK (Subgranon and Lund, 2000; Smith et al., 2004; Buschenfield, Morris and Lockwood, 2009; Greenwood et al., 2000a; Greenwood et al., 2009b; Katbamna et al., 2017). Three were from the USA (Bakas et al., 2002; Saban and Hogan, 2012; Danzyl et al., 2013). Two originated from Sweden (Backstrom and Sundin, 2009, 2010), another two from the Netherlands (Visser-Miely et al., 2008, 2009). One each were from Australia (El Masry, Mullan and Hackett, 2013), Austria (Van Dongen, Josephsson and Ekstam, 2014), Canada (Coombs, 2007), Iran (Gholamzadeh et al., 2015), Italy (Simeon et al., 2016) and Sri-Lanka (Wagachchige, Samarasinghe and Elgan, 2018).

The two main coping strategies highlighted in the literature are passive, also known as emotion-based coping strategies and active coping strategies. Passive coping strategies imply a tendency not to take any action when problems occur, whereas with active coping strategies individuals actively seek solutions when faced with problems (Lazarus and Folkman, 1984; Visser- Miely et al., 2005). Both passive and active coping strategies were reported by the participants in the studies.

Acceptance as a coping strategy was reported in three studies (Subgranon and Lund, 2000; Saban and Hogan, 2012; Van Dongen, Josephsson and Ekstam, 2014). In a qualitative study which was conducted as part of a larger study (n=46) by Saban and Hogan (2012) in the USA, the participants reported adapting to a new reality, which

included recognising the difficulty of caregiving and accepting the permanence of their changed lives. One participant in that study reported accepting her new life and highlighted that caregiving was neither positive nor negative, 'it is what it is' (Saban and Hogan, 2012: 8). Other coping strategies reported by the caregivers include their faith and religious beliefs (Bakas et al., 2002; Coomb, 2007; Danzyl et al., 2013; Gholamzadeh et al., 2015), adjusting by developing routines (Smith et al., 2004; Greenwood et al., 2009a), avoidance (Backstrom and Sundin, 2010), modifying past roles and setting goals (Danzyl et al., 2013), sense of moral obligation (Katbamna et al., 2017) and rest and relaxation (Subgranon and Lund, 2000). Prompt information from health and social care professionals and support from friends and families was reported as helpful for coping in the study by Cecil et al. (2011). In a qualitative study with 31 family caregivers in the UK (Greenwood et al., 2009b) (CASP score15), established caregivers (those with prior caring experience) identified coping strategies much sooner than caregivers who were new to the role.

Interestingly, in some studies where participants combined caregiving and paid employment, family caregivers mentioned employment as their means of coping. For instance, in a study by Backstrom and Sundin (2009) with nine family caregivers in Sweden, the participants described going to work as having a 'breathing space' (Backstrom and Sundin, 2009: 1480). This enabled the family caregivers to focus on other activities apart from caregiving. This was also reported in a qualitative Austrian study that utilised phenomenological interpretive methodology with three family caregivers (Van Dongen, Josephsson and Ekstam, 2014) (CASP score 17), where employment was viewed as a coping strategy. They reported escaping the caregiving

role by going to work. One participant in that study described employment as a source for regaining energy and as a distraction from domestic challenges. Another participant reported that socialising with colleagues at work reduced grief and made it possible to laugh at issues that worried her at home, thus contributing to her well-being (Van Dongen, Josephsson and Ekstam, 2014).

In contrast, family caregivers in other studies have reported heightened stress as a result of combining paid employment and the caregiving role (Lin et al., 2016; Simeone et al., 2016). The differences in the findings therefore suggest that individuals respond to caregiving in different ways depending on their personal circumstances and resources. In a quantitative study with spousal caregivers (n=211) in the Netherlands, Visser-Miely et al. (2009) (JBI score 17) noted that utilising passive coping strategies was associated with negative outcomes, whereas using active coping strategies and seeking social support were associated with reduced burden or depression. The authors suggested that understanding the different coping strategies utilised by stroke family caregivers is vital to identify how to best support them (Visser-Miely et al., 2009).

2.11 Quality appraisal of the reviewed studies

As described earlier in section 2.9, CASP tools were utilised to appraise the quality of the qualitative studies and JBI tools for quantitative studies. The quality ratings of the 37 qualitative studies ranged from 10 to 18 out of a possible score of 20. Six studies had a quality score of 18 whilst the scores of more than half of the studies (19) ranged between 15 to 17. All studies were considered to have selected an appropriate research method for their aim, however, the lower scores were because the authors

provided insufficient detail about their relationship with participants and the process of data analysis. The 15 quantitative studies were appraised with two JBI checklists. Eight were cohort studies and scored a maximum score of 17 and a minimum score of 14 out of a possible score of 22. The scores of the seven cross-sectional studies ranged from nine to 14 out of a possible score of 16. The low scores in the quantitative studies were due to sampling procedures not being clearly described and the lack of a clear hypothesis. Details of the quality ratings for the qualitative and quantitative studies are presented in Appendix 3 and 4 respectively.

2.12 Chapter summary

In summary, this narrative literature review chapter has presented an overview of the various challenges, support needs and coping strategies of stroke family caregivers, as identified in the qualitative and quantitative studies. It is evident from the literature that stroke family caregivers face numerous problems when providing care to stroke survivors in non-institutionalised settings. The sudden nature of stroke coupled with its chronicity makes it particularly challenging for this group of family caregivers. Therefore, to maintain the health and well- being of both the stroke survivor and their caregiver, stroke family caregivers require on-going support from health and social care professionals as well as their families and friends. This review has also highlighted the limited number of studies conducted with stroke family caregivers in developing countries. Furthermore, the ethnicity of caregivers was not routinely reported in the studies. It appears from the literature that the majority of the studies have been conducted with family caregivers from White ethnic groups. It is important that future research incorporates family caregivers from wider ethnic groups as their

caregiving experiences may be affected by ethnic and cultural differences. Since the focus of the current study was to develop the CAT-S for use with stroke family caregivers, in the next chapter, another narrative review of the literature will be presented, focusing on the assessment tools that are used to identify or assess the needs of the family caregivers of stroke survivors.

Chapter 3: Literature review of existing tools used to assess the needs and burden experienced by family caregivers of stroke survivors

3.1 Introduction

The previous chapter provided a review of the literature regarding the main challenges experienced by the family caregivers of stroke survivors. The current chapter will provide a review of the literature focusing on the existing tools that have been used to identify and assess the needs of and burden upon the family caregivers of stroke survivors.

3.2 Aim of the literature review

In accordance with the rationale for a narrative literature review provided in the previous chapter (Section 2.2), a second review of the literature was conducted to identify and describe existing tools that are used to assess the needs and burden of caregiving experienced by the family caregivers of stroke survivors residing at home.

3.3 Search strategy

To aid with the literature search, the PEO (population, exposure, outcome) framework (Khan et al., 2003) and the PICO (population, intervention, comparison, outcome) framework (Richardson et al., 1995) were devised (Table 5).

Table 5: PEO/PICO framework

Population	Family caregivers of stroke survivors living at home
Intervention/Exposure	Assessment of caregiver needs or burden using a validated tool
Outcome	Identified needs, burden as a result of caregiving or burden scores

In preparation for the registration viva in April 2015, a preliminary, computerised, search of the literature was undertaken in December 2014 covering the period 2004 - 2014. In November 2016, the literature search was expanded to cover the period 1980 - 2016. The year 1980 was specifically chosen as a cut-off period because it was around the early 1980s that a growing interest was expressed in documenting the caregiving experience using a variety of instruments intended to measure caregiver burden, needs and quality of life (Van Durme et al., 2012). Additionally, although the concept of burden was first introduced in the 1960s (Chou, 2000), studies on caregiver burden encompassing any period post-stroke, have been conducted since the mid-1980s (Byun and Evans, 2015). A final search of the literature was conducted in January 2019 covering the period 2016 -2019 to ensure that a comprehensive search was completed.

3.4 Search method

The following databases were searched: CINAHL, MEDLINE, AMED, BNI and PsycINFO. These databases were selected because they contain topics of interest to this review. The key search terms used were: stroke, caregiver, burden and assessment tools. Synonyms and related terms were considered and searched using

the Boolean ‘OR’ (e.g. stroke OR ‘cerebrovascular accident’). Truncation (*) was utilised to capture spelling variants (e.g. care* would capture ‘carer’ and also ‘caregivers’). The different concepts were combined by the use of the Boolean ‘AND’. The filter function was used to limit the articles to those published after 1980 and in the English language only. Please see Appendix 5 for a full search history. Additionally, the hand-searching of key journals which have a focus on stroke caregivers e.g. Disability and Rehabilitation, Rehabilitation Nursing and Clinical Rehabilitation as well as the reference lists of the selected studies was undertaken (Booth, Papaioannou and Sutton, 2016).

3.5 Inclusion and exclusion criteria

Articles focusing on stroke family caregivers only were selected for this review. Studies that included non-stroke family caregivers in their sample were excluded in accordance with the focus of this study. Furthermore, evidence suggests that stroke family caregivers have a unique experience due to the sudden onset of stroke and the limited time that they may have to adjust to the significant shift in circumstances (Mackenzie et al., 2007; Lincoln et al., 2011). Studies focusing on the single aspects of needs, such as information needs, or emotional needs only, were excluded as caregiver burden is a broad and multidimensional concept encompassing multiple aspects, such as physical, social, emotional and financial issues that can be experienced by caregivers as a result of providing care for someone (Zarit, Reever and Bach-Peterson, 1980; Rigby, Gubitz and Phillips, 2009). Family caregivers aged 18 years and above supporting stroke survivors living at home were included in this review as this was the target population of this study. Table 6 provides a summary of

the inclusion and exclusion criteria of the selected studies. See Appendix 6 for the studies included in this review.

Table 6: Summary of inclusion and exclusion criteria

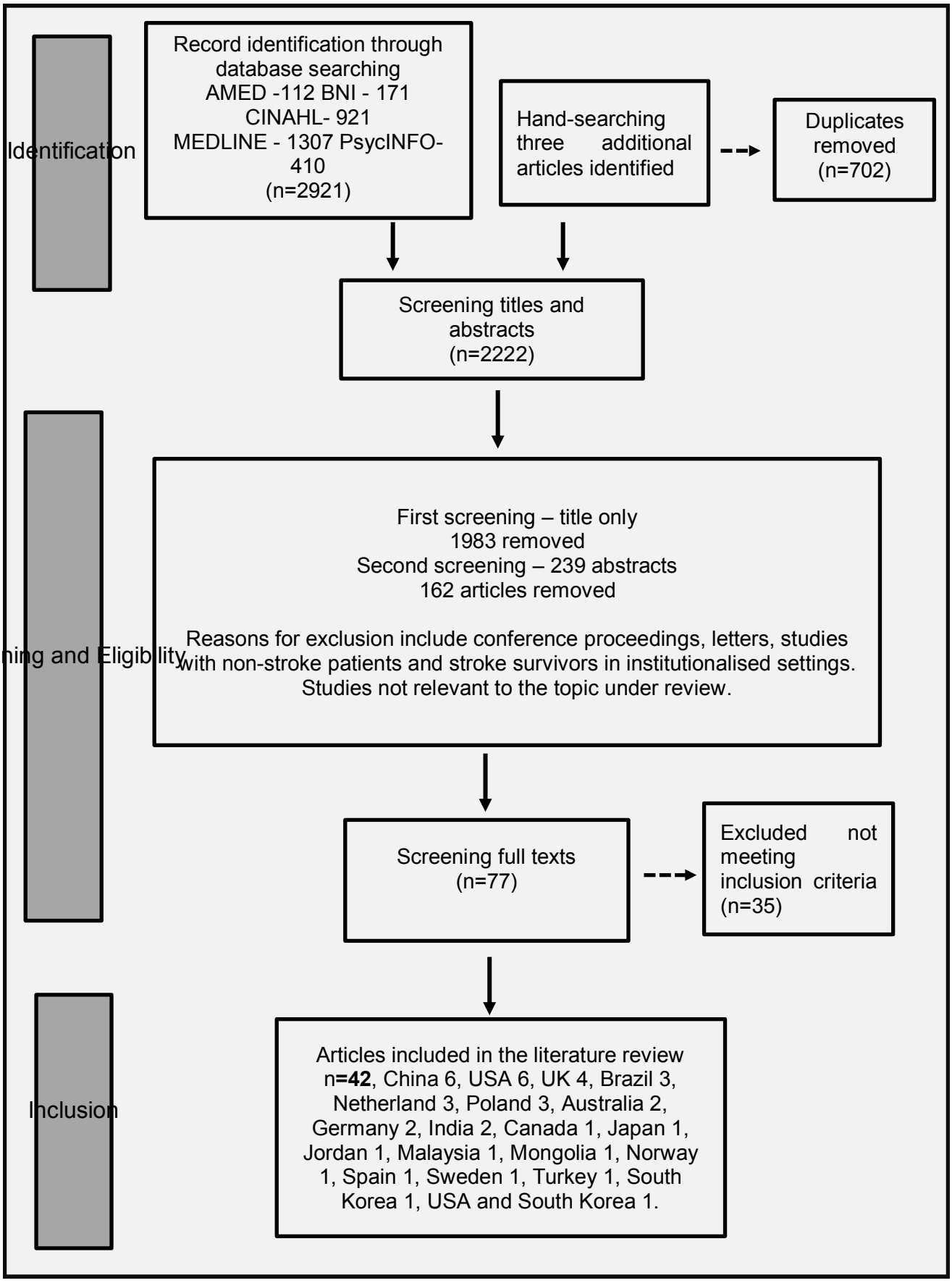
Inclusion	Exclusion
Family caregivers of stroke survivors living at home, caregivers aged 18 years and above	Family caregivers of stroke survivors in hospitals or institutionalised care settings e.g. residential or nursing homes; caregivers under 18 years of age; studies involving a mixture of stroke and non-stroke caregivers in their sample as well as paid caregivers
Studies with a primary aim of assessing caregiver burden or needs using an assessment tool	Studies with a primary focus of other caregiver interventions but that assessed caregiver burden or needs as an outcome measure; studies assessing the burden or needs of stroke caregivers using open-ended questionnaires; studies focusing on single aspects of needs e.g. information needs, emotional needs
Primary empirical studies with any clear methodology	Literature reviews and any papers without an explicit stated methodology e.g. opinion articles
Articles in the English language	Articles unavailable in English

3.6 Search results

The search yielded a total of 2,924 articles with 702 duplicated articles which were removed at the outset. A summary of the search results is provided in Figure 3. An initial screening of the titles of the remaining papers was undertaken, which resulted in the removal of 1,983 articles. A secondary screening of the remaining 239 papers was performed, which involved examining the abstracts and 162 articles were excluded. The main reasons for exclusion were articles that had a primary focus on

other caregiver interventions but assessed caregiver burden as an outcome measure, studies that included young caregivers under the age of 18, studies referring to the family caregivers of stroke survivors in institutionalised settings such as hospitals or nursing homes and studies solely focusing on the positive effects of caregiving. Literature reviews, letters and commentaries were also excluded. The hand-searching of key stroke rehabilitation journals as well as checking the reference lists of the selected publications yielded three additional articles (Evans, 1986; Op Reimer, 1998b; Kamel, Bond and Froelicher, 2012). The full texts of 77 articles were obtained and further scrutiny resulted in 42 articles that met the inclusion criteria and were included in this review. A systematic review on caregiver burden following stroke (Rigby, Gubitz and Phillips, 2009) was excluded from this review as it includes the caregivers of stroke survivors from different settings including those in hospital and institutionalised care settings and not specifically those residing at home as was the aim of this review. The reference list of the systematic review was however checked to identify any relevant studies, but this did not yield any additional articles. To minimise selection bias, the 77 articles that underwent full scrutiny were independently reviewed by the members of the supervisory team against the inclusion and exclusion criteria. Any disagreements were resolved through discussions until consensus was reached.

Figure 3: Summary of search results



3.6.1 Description of identified studies

The studies included in this review were undertaken in 19 different countries, as illustrated in Figure 3. The majority of the studies were conducted in Europe, Asia and North America. Three originate from South America (Brazil) and two from Australia. In a study conducted by Choi-Kwon et al. (2009), data was collected in two countries (the USA and South Korea). A summary of the studies and their location is provided in Appendix 6. All the family caregivers in the identified studies were supporting stroke survivors in non- institutionalised settings. Out of the 42 selected studies, 39 were quantitative studies, whereas three were mixed methods studies (Mackenzie, Holroyd and Lui, 1998; McKenna et al., 2013; Sedrez-Celich et al., 2016). Most studies employed a cross-sectional design, however, eleven were longitudinal studies (Blake, Lincoln and Clarke, 2003; Tooth et al., 2005; Ostwald et al., 2009; Vincent et al., 2009; King et al., 2013; Pfeiffer et al., 2014; Tsai et al., 2015; Jaracz et al., 2015; Han et al., 2017; Olivia-Moreno et al., 2018; Zhu and Jiang, 2018). The selected studies were published between 1986 and 2018.

The focus varied across the selected studies. Nine studies focused on the assessment tool in terms of tool development, piloting or psychometric testing of the tool within the stroke population. Five studies evaluated the prevalence of caregiver burden, whereas two studies (Perry and Middleton, 2011; Tsai et al., 2015) explored the needs of family caregivers following stroke. Another two studies were comparative studies (Choi-Kwon et al., 2009; Vincent et al., 2009), whereas one was an intervention study (Pfeiffer et al., 2014). The remaining studies either evaluated the determinants or potential factors that correlate with caregiver burden following stroke. A summary of the focus of the

studies is presented in Table 7.

Table 7: Focus of the identified studies

Focus of the identified studies	Studies
Tool development, piloting of the tool to test feasibility within the stroke population or psychometric testing.	Bakas and Champion, 1999; Elmstahl, Malmberg and Annerstedt., 1996; King et al., 2013; Lee and Mok, 2011; Mackenzie, Holroyd and Lui, 1998; Op Reimer et al., 1998a; Othman and Teck, 2014; Pendergrass et al., 2015; Post et al., 2007.
Prevalence of caregiver burden	Blake, Lincoln and Clarke, 2003; Das et al., 2010; Jaracz et al., 2015; Mackenzie et al., 2007; McKenna et al., 2013.
Determinants, predictors or factors associated with caregiver burden	Blake and Lincoln, 2000; Caro et al., 2018; Choi-Kwon et al., 2005; Chuluunbaatar et al., 2017; Denno et al., 2013; Evans, 1986; Han et al., 2017; Isaac, Stewart and Krishnamoorthy, 2011; Jaracz et al., 2012; Jaracz et al., 2014; Kamel et al., 2012; Macnamara et al., 1990; Morais et al., 2012; Morimoto, Schreiner and Asano, 2003; Olivia-Moreno et al., 2018; Op Reimer et al., 1998b; Ostwald et al., 2009; Sedrez-Celich et al., 2016; Tang et al., 2011; Thommessen et al., 2001; Tooth et al., 2005; Tosun and Temel, 2017; Zhu and Jiang, 2018.
Comparative studies	Choi-Kwon et al., 2009; Vincent et al., 2009.
Intervention studies	Pfeiffer et al., 2014.
Exploring the needs of family caregivers	Perry and Middleton, 2011; Tsai et al., 2015.

3.6.2 Data extraction and quality appraisal

A data extraction table was created (Booth, Papaioannou and Sutton, 2016) and the

key descriptive details of each study i.e. author, publication date, the country where the study was conducted, its focus, study design, the identified assessment tool used, and key findings were recorded (Appendix 6).

All the 42 selected studies were subjected to quality appraisal (Fink, 2014). The Joanna Briggs Institute (JBI) Critical Appraisal Tools were used to appraise the articles. As stated previously in the first narrative review, the tools were preferred as they provide a wider checklist for quantitative studies of various designs (JBI, 2017). Furthermore, they are widely used in the UK. Four JBI checklists were used during the assessment of literature: randomised control trial (13 items), analytical cross - sectional studies (8 items), prevalence studies (9 items) and lastly cohort studies (11 items). Since these tools do not have a scoring system, the scoring system previously described in Section 2.9 was adopted. With regards to the three mixed methods studies mentioned earlier in this chapter, only the quantitative component of the studies was included in this review as the qualitative aspects contained unrelated information to the purpose of this review. The JBI checklists mentioned above were therefore used to appraise these studies. Since the main aim of the review was to identify other tools that have been used with stroke family caregivers residing at home, a decision was made not to exclude any articles solely based on quality appraisal. The main intention of this quality assessment was to investigate and interrogate the studies systematically, to inform the current discussion and additionally to guide this study. All the selected studies provided clear research aims and the choice of research design was appropriate for answering the research questions. A summary of all included studies and their respective indicator of quality scores from the JBI tools is provided in

Appendix 6.

3.7 Review findings

Characteristics of family caregivers

The number of family caregivers included in the 42 studies ranged from 6-224, resulting in a total number of over 3,000 stroke family caregivers. The majority of the studies reported the full demographic details of the family caregivers such as age, gender, employment status and the relationship to the stroke survivor. The ethnicity of the caregivers was nevertheless reported in less than half of the studies (Evans 1986; Bakas and Champion, 1999; Choi-Kwon, 2009; Ostwald, 2009; Lee and Mok, 2011; Perry and Middleton, 2011; Tang et al., 2011; Kamel, Bond and Froelicher, 2012; Denno et al., 2013; Jaracz et al., 2014; Othman and Teck, 2014; Pfeiffer et al., 2014; Pendergrass et al., 2015). The ethnic groups of the caregivers in the selected studies include: African American, Chinese, Polish, White Australian, native German, Malay, Hispanic, White American, White British, Black and Asian among others.

Only a few studies provided the definition of a caregiver for their study. Out of the 42 studies, 16 studies reported this (Evans, 1986; Elmstahl, Malmberg and Annerstedt., 1996; Bakas and Champion, 1999; Blake and Lincoln, 2000; Blake, Lincoln and Clarke, 2003; Choi-Kwon et al., 2005; Mackenzie et al., 2007; Choi-Kwon et al., 2009; Ostwald, 2009; Lee and Mok, 2011; Perry and Middleton, 2011; Tang et al., 2011, Denno et al., 2013; Jaracz et al, 2014; Othman and Teck, 2014; Pfeiffer et al., 2014). Additionally, although all the included studies targeted family caregivers supporting stroke survivors living at home, about half of the studies reported on the living

arrangements of the caregiver and the stroke survivor; whether co-habiting with the stroke survivor or not (Bakas and Champion, 1999; Blake and Lincoln, 2000; Blake, Lincoln and Clarke, 2003; Choi-Kwon et al., 2005, 2009; Das et al., 2010; Denno et al., 2013; Jaracz et al., 2014, 2015; Kamel, Bond and Froelicher, 2012; Lee and Mok, 2011; McKenzie, Holroyd and Lui, 1998; Morimoto, Schreiner and Asano, 2003; Op Reimer, 1998a; Tooth et al., 2005; Othman and Teck, 2014). Consistent with the wider caregiving literature, the majority of family caregivers in all studies were female.

Patient characteristics

The characteristics of the stroke survivors such as demographic information, severity of stroke, functional status and cognitive impairment that may impact on the family caregivers' response to the experience of caregiving were also reviewed. All the studies except Morais et al. (2012) and Othman and Teck (2014) provided some information about the stroke survivor. However, variations were noted on how the different studies reported this information. In the study by Bakas and Champion (1999), stroke survivor characteristics were reported by family caregivers and included difficulties in speech and understanding, confusion and cognitive impairment. In 17 out of 42 studies, the patient's functional status was reported, and the Barthel Index (BI) and the Modified Rankin Scale (MRS) were the most commonly used instruments. Other tools that were used to report the patient's disability, severity of stroke and mood were the National Institute of Health Stroke Scale (NIHSS), Scandinavian Stroke Scale (SSS), Canadian Neurological Scale (CNS), Frenchey Activities Index (FAI), Functional Independence Measure (FIM), Extended Activities of Daily Living (EADL), Mini Mental State Examination (MMSE), Geriatric Depression Scale (GDS) and the

Hospital Anxiety and Depression Scale (HADS).

Timing of assessments

Differences were noted in the timing of assessments and this was usually reported either in terms of time since stroke or time since hospital discharge. This ranged from the day of discharge to up to 14 years post stroke. Two studies collected their data at six months post stroke (Jaracz et al., 2012, 2014). Another two studies collected data three years post stroke (Elmstahl, Malmberg and Annerstedt., 1996; Op Reimer et al., 1998b). In the study by Evans (1986) data was collected at one year following hospital discharge. None of the studies provided reasons why these time frames were chosen except for Jaracz et al. (2014), who reported that the six months timeframe was chosen because the functional status usually stabilises within the first six months post stroke which is simultaneously the most difficult time for caregivers. The remaining studies collected their data at variable timings post stroke or post hospital discharge.

As stated previously, eleven were longitudinal studies and the data collection was conducted at different time points. In four studies, data was collected at various time points within the first six months post stroke or following hospital discharge (Blake, Lincoln and Clarke, 2003; Vincent et al., 2009; Han et al., 2017; Zhu and Jiang, 2018). Five studies collected their data at various time points within the first 12 months (Tooth et al., 2005; Ostwald et al., 2009; King et al., 2013; Pfeifer et al., 2014; Olivia-Moreno et al., 2018). Tsai et al. (2015) focused on different times within the first three months following hospital discharge whereas Jaracz et al. (2015) collected their data at 6 months and five years following hospital discharge.

Identified tools

Twenty instruments or tools that are used to assess the needs and burden of caregiving were identified from the 42 articles. Table 8 provides a summary of the identified tools and the countries where they were developed. Please see Appendix 7 for a full list of the tools and their descriptions.

Table 8 : List of identified tools within the selected studies

Full name	Acronym	Author	Country
Abbreviated German Version of the Sense of Competence Questionnaire	SCQ-German	Pendergrass et al., 2015	Germany
Bakas Care-giving Outcomes Scale	BCOS	Bakas and Chapman, 1999	USA
Burden Assessment Schedule	BAS	Thara et al., 1998	India
Caregiver Burden Scale	CB Scale	Elmstahl, Malmberg and Annerstedt., 1996	Sweden
Care-giving Burden Scale	CBS	Gerritsen and Van der Ende, 1994	Netherlands
Caregiver Burden Inventory	CBI	Novak and Guest, 1989	Canada
Caregiver Reaction Assessment	CRA	Given et al., 1992, USA	USA
Carer Assessment Scale	CAS	Mackenzie et al., 1998	China
Carer Strain Index Carer Strain Index - Malay	CSI CSI-M	Robinson, 1983 Othman and Teck, 2014	USA Malaysia
Chinese Caregiver Task Inventory	CCTI-25	Lee and Mok, 2011, China	China
Family Needs Questionnaire	FNQ	Kreutzer and Marwitz, 1989, USA	USA
Measure of burden of caregivers of people with disabilities living at home	N/A	Dumont et al., 1998 (Original article in French)	Canada
Modified Montgomery Caregiver Burden Scale	Montgomery CGB Scale	Montgomery, Borgatta and Borgatta, 2000	USA
Obsert Caregiving Burden Scale	OCBS	Obsert, 1990	USA
Perceived Stress Scale	PSS	Cohen and Williamson, 1988	USA
Relatives Stress Scale	RSS	Greene et al., 1982	UK
Sense of Competence Questionnaire	SCQ	Vernooij-Dassen et al., 1996	Netherlands
Unmet Needs Resources Scale	URNS	King et al., 2013	USA
Zarit Burden Interview	ZBI	Zarit, Reever and Bach-Peterson, 1980	USA

The three most commonly used instruments within the selected studies were the Sense of Competence Questionnaire (SCQ) (Vernooij-Dassen et al., 1996), the Zarit Burden Interview (ZBI) (Zarit, Reever and Bach-Peterson, 1983) and the Carer Strain Index (CSI) (Robinson, 1983), which were used eight and seven times respectively within the reviewed studies. Six studies used more than one instrument (Blake and Lincoln, 2000; Tooth et al., 2005; Mackenzie et al., 2007; Post et al., 2007; Perry and Middleton, 2011; Denno et al., 2013).

Publication date and number of items

As illustrated in Table 8, most of the identified tools were developed before the year 2000. Six out of the twenty tools were published in the 1980s (CBI, CSI, FNQ, PSS, RSS and ZBI) whilst nine tools were published between 1990 and 1999 (BAS, BCOS, CB Scale, CBS, CAS, CRA, OCBS, Measure of perceived burden of caregivers of people with disabilities living at home and SCQ). It is important to note that although the CSI-M, CCTI-25, the abbreviated German version of the SCQ and the Modified Montgomery Caregiver Burden Scale were first published after the year 2000, these are the modified versions of the original tools that were all published before the year 2000. The URNS is the only tool that was originally published in 2013.

The number of items in each tool was also reviewed, as this could possibly provide insight into the amount of time required to complete the assessment. This ranged from 10 items (Perceived Stress Scale; Cohen and Williamson, 1988 and the 10-item BCOS; Bakas and Champion, 1999) to 41 items (Measure of perceived burden of the caregivers of people with disabilities living at home; Dumont et al., 1998). Eight tools

had more than 20 items (BAS, CBI, CB scale, CRA, CCTI, FNQ, SCQ, ZBI and a measure of the perceived burden of the caregivers of people with disabilities living at home) and ten had 11-20 items (BCOS, CAS, CBS, CSI, CSI-M, OCBS, Modified Montgomery Caregiving Burden Scale, the Abbreviated German version of SCQ, RSS and the URNS) (Appendix 7).

The time taken to administer or self-complete the tool was only reported in two studies, Op Reimer et al. (1998a) and Lee and Mok (2011). The average time to self-complete the SCQ (27 items on a 4-point scale) by the stroke partners was approximately 15-20 minutes and approximately 10 minutes by a trained research assistant during a telephone interview. Similarly, the average time to self-complete the CCTI (25 items on a 3-point scale) was approximately 15-20 minutes.

Caregiver population (tool development)

The majority of the tools were developed with the family caregivers of the patients with dementia (n=7) which included CBI, CBS, RSS, ZBI, SCQ and the CRA which had the caregivers of patients with Alzheimer's disease, physical impairments and cancer; the CB scale which had the family caregivers of patients with dementia and stroke. The BCOS, CAS, CCTI-25, the German Abbreviated version of the SCQ and the URNS were developed with stroke family caregivers. The remaining tools were developed with the family caregivers of psychiatric patients (BAS), elderly patients (CCTI and Montgomery CBG Scale), patients recently hospitalised for hip surgery or heart disease (CSI), traumatic brain injury (FNQ), cancer patients receiving radiotherapy (OCBS), residents of the US aged 18 years and older (PSS), and the caregivers of

people living with disability (Measure of perceived burden of caregivers of people with disabilities living at home). The CSI-M was a translation of the original CSI into Malay language with the stroke family caregivers being the initial test population. Furthermore, most of the tools were developed with family caregivers in the USA (n=9); BCOS, CRA, CSI, FNQ, Montgomery CGB Scale, OCBS, PSS, URNS and ZBI; Canada (n=2); CBI and measure of perceived burden of caregivers of people living with disabilities; the Netherlands (n=2); SCQ and CBS. The remaining tools were developed in the following countries: BAS (India); CB scale (Sweden); CSI-M (Malaysia); CAS and CCTI - 25 (China); the Abbreviated -SCQ (Germany) and RSS (UK).

Psychometric testing

To assess the validity of a scale, the evaluation of internal consistency through calculation of the coefficient of reliability (Cronbach's alpha) is commonly cited in the literature to allow comparison within studies. Cronbach's alpha of 0.70 and above indicates strong internal consistency (Rubin and Babbie, 2010). Less than half of the studies (n=16) provided data on tool validity within their population. Cronbach's alpha of above 0.70 was reported in each of the studies indicating high reliability of the identified tools within the stroke population (Table 9).

Table 9 : Table showing tool validity within the selected studies

Source	Tool	Cronbach's alpha
Bakas and Champion, 1999	BCOS	Sample1 - 0.90 Sample2 - 0.77
Choi-Kwon et al., 2009	SCQ	0.83
Denno et al., 2013	BCOS OCBS	0.944 0.938
Elmstahl, Malmberg and Annerstedt., 1996	CB scale	0.70 - 0.87
Jaracz et al., 2014	CB scale	0.9
King et al., 2013	URNS	Over 0.70
Lee and Mok, 2011	CCTI-25	0.93
Mackenzie et al., 2007	SCQ	0.90
Op Reimer et al., 1998b	SCQ	0.83
Ostwald et al., 2013	PSS	0.85
Othman and Teck, 2014	CSI-M	0.79
Pendergrass et al., 2015	SCQ-German Abbreviated	0.89
Perry and Middleton, 2011	CAS SCQ	0.85 0.88
Post et al., 2007	CSI CRA	0.93 0.97
Tosun and Temel, 2017	ZBI	0.82

Quality appraisal of the reviewed studies

As stated previously in section 3.6.2, four JBI checklists were used to appraise the quality of the 42 studies depending on the study design. Over half of the studies were cross-sectional studies. The quality ratings of the studies ranged from a minimum score of 10 to a maximum score of 15 out of a possible score of 16. This was followed by cohort studies which scored a minimum score of 16 to a maximum score of 22. Prevalence studies scored a minimum score of 14 and a maximum score of 15 out of the possible 18. The score for the only randomised control trial was 25 out of a possible score of 26. Details of the quality ratings for each study are presented in Appendix 6.

3.8 Discussion

Studies included in this review were undertaken in 19 different countries located on five continents (North America, South America, Europe, Asia and Australia). This suggests that research aiming to assess the needs and the burden of family caregivers following stroke is an important area with international interest.

Twenty tools that have been used to assess the needs and burden of caregiving experienced by the family caregivers of stroke survivors residing at home were identified from the selected articles. As stated earlier in this chapter, the three most commonly used tools within the reviewed studies were the CSI, ZBI and the SCQ. Similarly, these tools were identified in earlier reviews (Rigby, Gubitz and Phillips, 2009; Oliveira et al., 2012) suggesting their wider use in stroke research. Additionally, the only published guidelines for stroke family caregivers (Van Heugten et al., 2006) recommend that caregiver strain or burden needs to be adequately measured with a burden assessment tool such as the Carer Strain Index (CSI) (Van Heugten et al., 2006). Although the validity of the three tools has been established within the stroke population, there is however limited information on the usability of the tools in clinical practice. None of the studies reported the experiences of the personnel administering or completing these tools or the experiences of family caregivers. This may indicate the focus of the studies, targeting the use of the tools for measurement purposes by researchers rather than practitioners who require the tools for use in clinical practice (Mackenzie, Holroyd and Lui, 1998). Future studies therefore need to focus on the feasibility of these tools as well as the experiences of the stroke family caregivers and staff when completing these tools to allow service users and clinicians to make

judgements of whether to adopt these tools in clinical practice.

Furthermore, most of the tools identified in this review were developed in the 1980s and 1990s respectively with non-stroke populations. It can therefore be argued that research focusing on more recent tools is required locally and internationally to establish the current priorities and needs of family caregivers as these may have changed over time. This is particularly relevant in the context of stroke where massive changes in the treatment and management of stroke have taken place in the last two decades due to the advances in the treatment for stroke discussed in Chapter 1.

Out of the twenty tools identified in this review, five were developed with the family caregivers of stroke survivors (BCOS, CAS, URNS and Abbreviated (shortened) German version of the SCQ and the CCTI-25). Although the CB scale (Elmstahl, Malmberg and Annerstedt., 1996) was also developed with some stroke family caregivers, their sample included the family caregivers of patients with dementia who accounted for more than half of the total sample (n=83 / 150). Nevertheless, the five stroke specific tools do not seem to be popular within the selected studies. For instance, in the 42 studies, the BCOS was used only three times, the CAS was used twice, and the other three more recent tools (URNS, CCTI-25, SCQ-German) were used once. It can however be argued that although the URNS, CCTI-25 and the SCQ - German could potentially be relevant for use in the UK in the context of research, their relevance to practitioners, staff and stroke family caregivers may be limited due to different health and social care provisions in the countries where the tools were originally developed (USA, China and Germany). For example, the URNS (King et al.,

2013) which was developed for use with stroke family caregivers in the USA, contain three items concerning internet use and a website which may not be a priority for stroke family caregivers in the UK.

It is also important to note that among the stroke-specific tools identified in this review, there was minimal input and consultation from family caregivers during the development of the tools. For instance, during the development of the BCOS (Bakas and Champion, 1999) the items were selected by five experts (all health professionals) and did not include any family caregivers. Similarly, the developers of the CCTI-25 (Lee and Mok, 2011) had six experts which included one family caregiver with the rest being health and social care professionals. In the remaining stroke-specific studies (URNS, CAS and SCQ- German), the family caregivers were mainly involved during the piloting phase of the tool development. Although family caregivers may be a hard to reach population (Carers UK, 2017), it can be argued that their full involvement and obtaining their perspectives during the development of the tools, particularly selecting the content of the tools is required to ensure that the tools include the priorities of the family caregivers and not just those of health and social care professionals and researchers.

Tool administration within the selected studies was either undertaken by a research assistant through face-to-face interviews or over the telephone in addition to being self-administered by family caregivers. All 20 tools appear to be suitable for use as self-report questionnaires or interviews although they vary in length. Overall, the most commonly used tool in the selected studies was the SCQ which has 27 items. The

number of items on the tools raises questions about the time taken to complete the assessment and the risk of potentially overburdening family caregivers with long questionnaires. Short questionnaires must therefore be preferred if possible, especially when psychometric testing is satisfactory (Van Durme et al., 2012). Short, easy to complete tools are therefore required to aid with triaging stroke family caregivers and assist staff in referring family caregivers to appropriate services.

It was noted from the reviewed studies that family caregivers were not adequately described. In most studies, it was impossible to determine whether family caregivers were co-habiting with the stroke survivors or not. It is inappropriate to assume that all family caregivers will have similar problems and needs. For instance, there is evidence suggesting that caregivers who live with the person for whom they care are particularly at risk of experiencing difficulties in their caregiving role (Hirst, 2004; Petrie and Kirkup, 2018). Additionally, very few studies provided information regarding the ethnicity of family caregivers. It is therefore important that in future studies, the ethnicity and living arrangements of the family caregivers (whether co-habiting with the stroke survivor or not) is provided to allow valid conclusions and judgements to be made (Greenwood et al., 2009a).

As previously mentioned in Chapter 1, identifying and supporting the needs of family caregivers remains a priority in the UK. Although some stroke specific tools have been identified in this review, none of the tools appear to be suitable for use in clinical practice settings in the UK. Some authors have argued that instruments concerning the needs of family caregivers should be developed in the cultural settings where they

are to be used, as relationships and culture will result in different needs being paramount (Twigg, Atkin and Perrin, 1990; Lee and Mok, 2011). None of the identified stroke-specific tools were developed in the UK. Furthermore, none of the identified tools offer guidance regarding support and action points that may be provided to family caregivers and may thus limit their potential use by practitioners and staff in the UK.

Strengths and limitations of the identified tools

All the tools included in this review have usefulness for the purposes that they were designed to address. Furthermore, as illustrated in Table 9, the majority of the tools have undergone psychometric testing indicating high reliability of the tools within the stroke population (Streiner, Norman and Cairney, 2015), thus making them valid for use in the context of research. Additionally, out of the 20 identified tools, five were developed with family caregivers of stroke survivors. Some authors have argued the importance of disease-specific tools over generic tools as they tend to contain more relevant questions which may be useful at detecting changes within that population (Streiner and Norman, 2009). Therefore, it can be argued that both generic and disease-specific tools currently exist that are valid for use with stroke family caregivers in the context of research.

However, there are some limitations to note from the identified tools which may limit their use in clinical practice settings in the UK. As illustrated earlier in this chapter (Table 8), out of the 20 tools, the Relatives Stress Scale (RSS) (Greene et al., 1982) was developed with family caregivers of patients with dementia in the UK. It is therefore unlikely for the RSS to be relevant for use in clinical practice as the needs of

family caregivers of dementia patients are not representative of the needs of stroke family caregivers due to the different disease trajectories of the two medical conditions. Additionally, although five stroke specific tools were identified, none of the tools were developed in the UK. This could limit their use in the UK due to cultural differences that exist within the countries. Furthermore, each country has their own legislative framework regarding assessing the needs of family caregivers and the support available. It was further noted that there was minimal involvement of family caregivers during the development of the tools, particularly in selecting the items to be included in the tools.

None of the tools identified in this review offer signposting or suggestions for further action or interventions. Evidence suggests that lack of information on availability and access to services for patients and their family caregivers can lead to perceived marginalisation (Pindus et al., 2018). It is thus recommended that appropriate action plans, referral pathways and knowledge of support services are considered when assessing the needs of stroke survivors and their family caregivers (Turner et al., 2019).

A major limitation of this review is that it only focused on studies assessing the needs and burden of the family caregivers of stroke survivors residing at home. As a result, other studies that had a mixture of family caregivers of hospitalised or institutionalised stroke survivors in their sample were excluded from this review. In addition, due to the search strategy used, it is possible that other assessment tools may have been overlooked where the name does not include the terms ‘needs’, ‘strain’ and ‘burden’,

or where this could not be clearly derived from the abstract. Language bias is another limitation of the review. Only studies published in English were included.

3.9 Conclusions

This review has identified 20 assessment tools that have been used to assess the needs and the burden of caregiving experienced by the family caregivers of stroke survivors living at home. Although some stroke-specific tools were identified, none of the tools appear to be suitable for use in clinical practice in the UK with stroke family caregivers. In addition, there was minimal involvement of family caregivers in selecting the items included in the tools. The CAT described in Chapter 1 is a more recent screening tool, which was developed with family caregivers in the context of end-of-life care in the UK. In view of the ongoing challenges with carer assessment discussed earlier in this thesis, the CAT-S has considerable potential, particularly its function as a triage tool to assist in prioritising family caregivers in need of a formal assessment by professional staff. Furthermore, since the CAT-S can be used by a range of non-specialist personnel, in the current climate of limited resources, it offers opportunities within existing resources for staff to identify family caregivers in need of support much sooner before reaching a crisis point. Most importantly, the CAT-S offers signposting or suggestions for further actions. Feedback received from the small pilot that was done to test the feasibility and usability of the CAT-S suggests that it is valuable in identifying and supporting the needs of family caregivers of stroke survivors.

It is important to note that although at the outset of this study, no stroke-specific tool

was identified for use in clinical practice settings in the UK, since then, another tool specifically for use with stroke family caregivers called the Carer Support Needs Assessment Tool for Stroke (CSNAT- Stroke) has been developed in the UK (Patchwood et al., 2019). Although the results of the CSNAT-Stroke study have not yet been published, the CSNAT-Stroke adapted from the original CSNAT developed in the context of palliative care (Ewing et al., 2013) differs from the CAT-S, which was developed in this study. The CSNAT-Stroke is a comprehensive assessment tool and not a short screening tool as is the case for CAT-S. Additionally, no data has yet been reported about the completion times of the original CSNAT tool (Ewing et al., 2013) and this may potentially pose additional challenges regarding its uptake in clinical practice. The CAT-S was designed as a brief screening tool for use by a wide range of non-specialist personnel and may potentially assist in overcoming some of the challenges related to carer assessment discussed earlier. This study therefore aimed to adapt the CAT and develop CAT-S for use with stroke family caregivers. The following section will outline the research question and objectives of this study.

3.10 Research question and objectives

The first three chapters have provided an overview of the literature detailing the effects of stroke on individuals, the challenges experienced by stroke family caregivers and the tools that have been used to identify the needs and burden experienced by stroke family caregivers. The challenges regarding the existing approaches to assessments have been re-affirmed by findings from Carers UK and support the use of a screening tool to assist in prioritising family caregivers in need of support. As a result, the following research question and objectives were created:

Research question

How can the views and experiences of family caregivers of stroke survivors and staff working within stroke services be incorporated to adapt the CAT and develop the CAT-S?

Research objectives

1. To explore the experiences of the stroke family caregivers of the factors contributing to burden during caring following stroke.
2. To seek the views of stroke family caregivers on the items of the original CAT.
3. To gain consensus from stroke family caregivers and staff working within stroke services on the most important factors to be included in the CAT-S.
4. To pilot the CAT-S to test feasibility of recruitment, methods of data collection, its usability and usefulness in practice to identify stroke family caregivers needs for those supporting stroke survivors.
5. To explore the experiences of stroke family caregivers and community- based stroke coordinators when using the CAT-S.

3.11 Chapter summary

This chapter aimed to identify existing tools that have been used to identify the needs and burden experienced by family caregivers of stroke survivors. Overall, 42 articles were included in this review and 20 tools were identified. Although five stroke-specific tools were identified none of the tools were deemed appropriate for use with family caregivers in clinical practice in the UK. Furthermore, none of the tools identified as a screening tool. However, it was identified that the CAT-S has the potential as a triage tool to assist in prioritising family caregivers in need of formal assessment and supporting family caregivers before reaching a crisis point. The subsequent chapter will discuss the methodology that was adopted for the current study.

Chapter 4: Methodology

4.1 Introduction

In this chapter, the methodological approach that was adopted for this study will be presented. Firstly, the history of action research and its philosophical foundations will be outlined. This will be followed by the definition of action research and its key components, the different approaches of action research, action research in healthcare and the justification for adopting action research methodology. The processes that were followed will be described using the framework outlined by Meyer (2010). The chapter concludes with the limitations of using action research as well as the criteria used to assess the quality of action research studies.

4.2 Methodological considerations

In order to address the aim and objectives of this study as stipulated in the previous chapter, a multi-phase study, utilising both qualitative and qualitative methods underpinned by principles of action research was adopted (Waterman et al., 2001; Meyer, 2010). Pragmatism (Powell, 2001, Johnson and Onwuegbuzie, 2004; Creswell, 2013) which legitimises the mixing of qualitative and quantitative approaches to ensure that research questions are answered in the most effective way could have been adopted. Furthermore, translational research (Fontanarosa and Deangelis, 2002; Woolf, 2008), where there is effective translation of new knowledge in one area to another was considered. For instance, in the context of the current study, the aim was to adapt the Carers Alert Thermometer (CAT) (Knighting et al., 2015) originally developed in the context of palliative care to develop the CAT-S specifically for use

with family caregivers of stroke survivors. Nonetheless, action research was preferred due to its participatory and democratic nature (Meyer, 2000). It was deemed important that the resultant CAT-S developed from this study is owned by the target population (i.e. stroke family caregivers and staff working within stroke services) to facilitate its quicker adoption into clinical practice (Black, 2006). The choice of action research thus facilitated this active engagement with stakeholders not always possible with alternative approaches. Additionally, the current study also drew upon instrument development research (Streiner and Kottner, 2014; Streiner Norman and Cairney, 2015) since the overall aim was to develop the CAT-S for use with stroke family caregivers.

4.3 History of action research

The roots of action research date back to 1946 and Kurt Lewin (1890-1947) is credited with devising the term 'action research' (Reason and Bradbury, 2001; Greenwood and Levin, 2006). Lewin was a Prussian psychologist who held left-wing political views and it is argued that his approach to research emerged from these political beliefs. He was interested in working collaboratively with employees and their managers in order to understand and study the problems affecting them. Lewin criticised his contemporaries' disconnected academic research, claiming that *'research that produces nothing, but books will not suffice'* (Lewin, 1946:35). He conceptualised action research as a spiral methodology, involving discrete phases, each consisting of circles of planning, action and the evaluation of the result of the action (Lewin, 1946).

According to Gunz (1996), other authors should also take credit for the development

of action research as is the case of Jacob Moreno (1892-1974), who was a physician, a social philosopher and a poet. He shared students with Lewin and reported the importance of integrating theory and practice by perceiving researchers as social investigators rather than just observers (Gunz 1996; Waterman et al., 2001). Collier also working in America, was using the terminology of action research in his work on race relations as Commissioner of Indian Affairs (Ebbutt, 1985). In the United Kingdom, according to Hopkins (2002), the origins of action research can be traced back to the Humanities Curriculum Project (1967- 1972) with its emphasis on an experimental curriculum and the re- conceptualisation of curriculum development. Lawrence Stenhouse is acknowledged for reawakening interest in action research in the field of education through the Humanities Curriculum Project. In turn, educational action researchers including Elliot (1991) have influenced action researchers in healthcare settings. Hart and Bond (1995) suggested that Lewin's work was highly influential in industrial and organisational action research.

4.4 Philosophical foundations

The philosophical foundations of action research have been informed by a number of ideologies including critical theory, naturalistic enquiry and phenomenology. In particular, the work of Jürgen Habermas on critical social theory provides a theoretical orientation for action research. Habermas proposed that knowledge was not simply developed through scientific intellectualism and the abstract pursuit of more knowledge. Rather knowledge development evolved from the interests and needs of humans in the context of their day-to-day experiences (Habermas, 1974; Carr and Kemmis, 1986). Furthermore, his concern was not simply in generating knowledge

that illuminated human experience, providing *'uncritical renderings of individuals' self-understandings'* but to understand knowledge as pivotal to change (Carr and Kemmis, 1986:137). He emphasised the need to critically reflect on individuals' understanding, not simply to identify cause and effect, but so that social issues and problems could be clarified and addressed (Habermas, 1974).

Critical social theory offers an ideology which is emancipatory in nature. Habermas built his theory around communicative interaction which inherently and unconditionally includes all humanity (Dickens, 1983). He believed that *'ultimate principles such as freedom, truth and justice are inherent in the very structures of communication (speech)'* (Dickens, 1983:145). He also believed that self-reflection and self-understanding must be interpreted within the context of the conditions in which they were formed. Habermas' approach sought to allow individuals to reflect on why issues and problems exist and then consider the type of action necessary to address these issues within the context of their own experience (Carr and Kemmis, 1986). In a systematic review of action research, Waterman et al. (2001:14) concluded that critical theory provided a philosophical foundation *'where the necessary interdependence of subjective and objective perspectives, individual and social perspectives and practice and theory are embraced'*. In this way, action research draws upon critical theory by providing people with a means to reflect on their experiences and act on their own problems in order to bring about change (Waterman et al., 2001).

4.5 Definition of action research

Articulating a universal definition of action research is not straightforward because of

the variety of descriptions, classifications and applications of the term offered in the literature. Munn-Giddings et al. (2008) identified 24 different terms to describe action research including collaborative action research, emancipatory and enhancement action research, participatory action research and evaluative action research. Most definitions of action research focus on the characteristic elements of the research process. For example, McTaggart (1991) explains that action research is collaborative in nature, requiring that people affected by the proposed changes be involved in decisions concerning actions. Additionally, Kemmis and McTaggart (1982) state that action research provides practitioners with a means to deal with problems they face in practice whereas, for Holter and Schwartz-Barcott (1993), action research is regarded as a means of bridging the gap between theory and practice.

On the contrary, other authors such as Hart and Bond (1995) argue that consolidating a single definition of action research may be prescriptive and ultimately restrictive. Nevertheless, in a systematic review of the literature regarding action research, Waterman et al. (2001) concluded that action research could be summarised by identifying a number of defining features that are common across the contemporary literature. As a result of their review, following an extensive reflection on the literature and subsequent investigations, they synthesised a definition of action research which underpins the research conducted in this study.

> *'Action research is a period of inquiry, which describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem- focused, context- specific and future oriented. Action research is a group activity with an explicit critical value basis and is founded on a partnership between action researchers and participants, all of whom are involved in the change process. The participatory process is educative and empowering involving a dynamic approach in which problem*

identification, planning, action and evaluation are interlinked. Knowledge may be advanced through reflection and research, and qualitative and quantitative research methods may be employed to collect data. Different types of knowledge may be produced by action research, including practical and propositional. Theory may be generated and refined, and its general application explored through the cycles of the action research process' (Waterman et al., 2001:11).

Furthermore, Waterman et al. (2001) state that there are two criteria that are linked and fundamental to all action research approaches. They are the partnership between the participants and researchers as well as a cyclic process involving some sort of change intervention. Most authors of action research add that reflection is also a key component and should always be present in all action research projects (Kemmis and McTaggart, 1982; Webb, 1989; Meyer and Cooper, 2015). These three key components, i.e. cyclic process, research partnership and reflection, will be discussed next.

4.6 Key components of action research

4.6.1 Cyclic process

The process followed in action research is typically described as cyclic. Authors such as Carr and Kemmis (1986) described action research as a spiral of cycles and this highlights that it is a linked process, with movement and connection from one aspect to the next. They argue that it is not a linear process with a beginning and an end, through which distinct phases are passed. It is described as cyclic because the research process may be ongoing and further problems identified and the cycle followed several times until the problems are resolved (Waterman et al., 2001; Winter and Munn- Giddings, 2001).

A variety of terminologies are used in the literature to describe the phases in the action research cycle. For example, Kemmis and McTaggart (1982:6) outline four distinct phases of 'planning, action, observation and reflection'. Additionally, Stringer (1996:17) describes a cycle of 'look, think and act', whereas Winter and Munn-Giddings (2001) propose that phases include critical reflection, action, data collection and further critical reflection. However, regardless of the terminology used, consistent with all action research is the movement between problem identification, including analysis and planning, the development of an action and evaluation (Waterman et al., 2001; Meyer and Copper, 2015).

The cyclic model of action research provides a theoretical framework which enables the researcher to interact within a specific context to explore a situation and enable change. In practice, however, the movement between the phases may be difficult to discern and at times occurs simultaneously (Waterman et al., 2001). The rapid movement of the research process has been described as 'cycles within cycles' and as a mini-spiral (Horner, 2005). Action research reflects a flexible and dynamic research process that is able to continuously respond to real-world demands, generating knowledge and action together, and reducing the discrepancy between theory and practice (Waterman et al., 2001).

4.6.2 Partnership

According to Waterman et al. (2001), the research partnership between the participants and the researchers is another key component of action research; those who are being studied are included as 'co-researchers' in the research process (Koch

and Kralik, 2006; Meyer and Cooper, 2015). Additionally, Webb (1990) views action research as a very different approach to research; not the smash and grab approach, where the researcher enters a situation, grabs the data required and leaves again. Rather it is about working together with the participants on an equal basis. In action research, participation is linked to ideas of democracy and the belief that people should participate or be consulted about healthcare decisions (Waterman, 2007). Compared with traditional approaches to research, where research participants play a passive role, the participants in action research are active. One benefit of this is that it can make the research process and outcomes more meaningful to practitioners by rooting these in the reality of day-to-day practice (Meyer, 2000, 2010). Throughout the research process, the findings are fed back to participants for validation. According to Mc Niff (1988), all elements of action research should involve democratic collaboration between the researchers and the participants, namely information sharing, systematic inquiry, reflection and action with the expected outcome of meaningful change.

Six categories of participation are proposed by Cornwall (1996), namely co- option, compliance, consultation, cooperation, co-learning and collective action. The degree of participation varies in practice depending on the aim of the action research project, the phase of the project, the experience of the researchers, the philosophical approach, personal factors and financial and human resources (Waterman et al., 2001; McNiff, 2013). The modes of participation in this study included consultation, cooperation and co-learning. These are presented later in Chapter 5.

4.6.3 Reflection

Group and individual reflection is a key component of action research (Kemmis and

McTaggart, 1982; Winter and Munn-Giddings, 2001). This is reinforced by Carr and Kemmis (1986:162) who state that action research is simply:

> *'A form of self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own practices, their understanding of these practices, and the situations in which these practices are carried out'.*

Reflection in action research binds together all activities associated with the research process and leads to empowerment and action (Waterman, 2007). It

enables research participants (including the researcher) to question their assumptions and habitual ways of thinking and working. As a result, syntheses of different perspectives occur over time both in groups and individually. By drawing on experiences and integrating these with other types of evidence, conclusions can be drawn about how, and why, practice could be changed (Waterman, 2007). Reflection as part of action research is therefore for all of those collaborating to bring about change. Because of this, the importance of management, and not just practitioners, being part of this reflective process is fundamental in order for change to occur (Koshy, Koshy and Waterman, 2010).

4.7 Different approaches to action research

Some researchers have proposed typologies of action research (Grundy, 1982; McKernan, 1991; Holter and Schwartz-Barcott, 1993; Hart and Bond, 1995; Coughlan and Brannick, 2001). These have focused on different aspects of the research process such as the level of focus, the degree of participation and the vision of knowledge (Whitelaw et al., 2003). A comparative table to show the distinct types described by

different authors is presented in Table 10. All have attempted to clarify how the aims of action research might best be matched by the approach taken by researchers. The typologies of Holter and Schwatz-Barcott (1993) and Hart and Bond (1995) have been widely used in the healthcare and nursing literature. These two typologies will be presented in the next section together with their relevance to this study.

Table 10 : Various descriptive action research typologies

Author	Modest orientation towards emancipatory orientations			
Grundy (1982)	Technical action research		Practical action research	Emancipatory action research
Mckernan (1991)	Action research as a scientific technical view of problem-solving		Action research as a practical deliberative process	Action research as a critical emancipatory process
Holter and Schwatz-Barcott (1993)	Technical collaborative approach		Mutual collaborative approach	An enhancement approach
Hart and Bond (1995)	Experimental	Organisational	Professionalising	Empowerment
Coughlan and Brannick (2001)	Experimental		Hermeneutic	Participatory

4.7.1 The typology of Holter and Schwatz-Barcott

The technical approach

The technical approach has been described as a natural science type inquiry (Holter and Schwartz-Barcott, 1993). The underlying goal of the researcher in this approach is to test a particular intervention based on a pre-specified theoretical framework. The aim is to identify if the intervention can be applied to practice. Although the intervention is defined in advance, researchers may introduce changes to the initial plan based on insights into the situation gathered during the action research process. Researchers

seek interaction with practitioners in order to gain their agreement to participate and their help with the implementation of the intervention.

The mutual collaborative approach

This approach is based on the historical-hermeneutical paradigm (Holter and Schwartz-Barcott, 1993). It involves the researcher and practitioners jointly identifying potential problems, their underlying causes and the possible interventions. The outcome of this approach is that practitioners and researchers achieve a new common understanding of the problem and its causes and agree on ways to initiate change. This approach promotes a more equal involvement between the parties involved and has the ability to produce more durable change; furthermore, it can result in the development of new theory. The knowledge generated by this type of research is mainly practical and emerges from the reflection of the practitioners on their own practice.

The enhancement approach

The enhancement approach is based on the critical science paradigm and aims to enable practitioners to use theory to explain and resolve problems. It also aims to raise awareness in practitioners regarding their underlying values and beliefs, both personal and collective, which are manifested within the organisational culture and may impact on the problems identified (Holter and Schwartz-Barcott, 1993). The strength of the typology presented by Holter and Schwartz-Barcott (1993) is that it provides a basis to distinguish action research approaches according to the researcher's philosophical position. Whilst acknowledging some strength within this typology, Hart and Bond (1996) also identify some limitations. For example, the Holter and Schwartz-Barcott (1993) typology does not consider that action research has a dynamic nature and

deals with action research projects as though they were static. However, this is not always the case as the direction of an action research project may change during the course of the study with the potential for action research to engage in different approaches as the study progresses. For this reason, the use of the typology by Holter and Schwartz-Barcott (1993) for this action research study was rejected.

The typology of Hart and Bond

An alternative typology devised specifically for health and social care is suggested by Hart and Bond (1995). Some authors view this typology as the most comprehensive and accomplished action research typology (Whitelaw et al., 2003; Meyer, 2010). Hart and Bond present seven criteria which they argue distinguish action research from other methodologies (Figure 4). Upon closer examination of this criterion, one element could reasonably be viewed as missing. That is the importance of reflective processes within criterion number six, i.e. the cycle of research, action, and evaluation. Reflection could be assumed to be part of evaluation; nevertheless, some authors emphasise the importance of specifically highlighting reflective processes as an essential element to action research (Kemmis and McTaggart, 1982; Meyer, 1993; Badger, 2000).

Figure 4: Seven distinguishing factors of action research (Hart and Bond, 1995:37)

1. It is educative
2. It deals with individuals as members of social groups
3. It is problem-focused, context-specific and future-oriented
4. It involves a change intervention
5. It aims at improvement and involvement
6. It involves a cyclic process in which research, action and evaluation are interlinked
7. It is founded on a research relationship in which those who are involved are participants in the change process.

Based on these characteristics, Hart and Bond (1995) identified four approaches to action research, namely experimental, organisational, professional and empowerment. The typology is set against a continuum ranging from a consensus view of society through to a conflict view, from rational social management through to challenging the structure of society.

In their typology, Hart and Bond (1995) track the historical progression of action research as a strategy from the experimental work of Lewin through to feminist approaches within social communities. Although not offering a definition of action research, the typology does make explicit the identified characteristics of action research, attempts to clarify action research types and avoids the problems associated with narrow definitions (Waterman et al., 2001).

The experimental approach

The experimental approach is associated with early days of action research and the scientific approach to social problems. Here the problem is defined in relation to a pre-established theoretical framework and is brought into practice by the researcher to be tested. Change is seen as a rational activity, planned and controlled. The problem is to be solved in terms of research aims and the researcher and participants have clearly defined roles. According to Hart and Bond (1995), this approach is closely aligned to the technical collaborative approach of Holter and Schwartz-Barcott (1993).

Organisational approach

The organisational approach focuses on organisational problem-solving usually

defined in terms of management interest. Change tends to be top- down and is directed towards pre-determined aims. There is a focus towards tangible outcomes, which are usually predefined. Education and training are seen as a means to bring about change in behaviour. Within this approach, there may be a tension between research and action, arising from a dual aim on the part of the consultant-researcher to meet the requirements of both managerial problem-solving and social science research (Hart and Bond, 1995:46). Action components are dominant in this type of research. According to Hart and Bond (1995), this approach is related to the mutual collaborative approach of Holter and Schwartz-Barcott (1993).

The professionalising approach

This approach is professionally led and is concerned with professionals' advancement together with the development of research-based practice. The problem selected for action research is negotiated between the researcher and users and emerges from professional practice. Education is understood as reflective practice. The research components are dominant in this type of action research. The researcher's and practitioner's roles are merged, as a consequence, the latter are seen as collaborators. This approach is related to the enhancement approach of Holter and Schwartz-Barcott (1993).

Empowering approach

The empowering approach is associated with community development approaches and empowering oppressed groups. Education takes the form of consciousness-raising in which, instead of relying on abstract knowledge, learning is rooted in the

everyday experience of vulnerable groups. The problem and objectives of the study emerge from the group and are usually undetermined as it uses a bottom-up approach. This approach, however, brings with it the possible danger of powerful groups not being involved (e.g. managers), thus creating potential blocks to progress in the future. The action components are dominant with this approach and the relationship between the researcher and practitioners is one of co-agents or co-researchers (Hart and Bond, 1995).

Unlike Holter and Schwartz-Barcott (1993), Hart and Bond (1995) stress that the use of an action research approach is not static and during the course of an action research project, it may shift from one type to the other as it moves through the spiral of cycles. For example, in the study Hart and Bond (1995) conducted, the organisational approach they used at the beginning changed towards an empowering type later on as the project developed and the practitioners became actively involved.

Nevertheless, drawing on the different approaches of action research suggested by Hart and Bond (1995) requires considerable knowledge and experience of action research. It may also appear to nullify the importance of a theoretical framework for research. Waterman et al. (2001:11) attempted to use Hart and Bond's typology to categorise studies in their systematic review of action research but found that it did not accurately reflect the findings in the included studies. They concluded that the action research that was part of the systematic review did not fall into distinct types, whilst acknowledging that Hart and Bond (1996) had not argued that their typology was ideal or prescriptive of action research.

The Hart and Bond typology did, however, appear to offer possibilities with regard to the aims of this study. At the beginning, the approach selected was arguably experimental in nature as the outcomes were pre-established and controlled by the researcher. This selection was made after taking into account the context in which the research was to take place. The study was to be conducted part of a research degree and therefore there were time and resource constraints to complete it within a specified period; as a result, a more controlled approach was thought to help achieve the research aim and objectives. This study, however, also shares some elements of the professionalising type because the principles that inspired this action research project are those of practice development. The researcher is a stroke nurse by background and therefore committed to the advancement of practice supported by evidence. However, in order to achieve this aim, an exploration and understanding of the problems at hand is required, which in this aspect of Hart and Bond's typology would be more associated with the empowerment approach.

In conclusion, there are different approaches to action research, the appropriateness of each one depending on the aims of the study and the context within which the study is conducted. Precisely because it is context- based research and takes place in a real situation, it is not surprising for action research to adopt different approaches during the course of a study (Meyer, 1993).

4.8 Action research in health and social care

Over the years, action research has continued to develop and has been adopted by several disciplines most notably in education, management and health and social care

(Waterman et al., 2001). In health and social care, action research has gained popularity as an appropriate methodology (Hart and Bond, 1995; Waterman et al., 2001; Meyer, 2010). Some authors including Webb (1998), Meyer (1993) and Waterman (1995) have described the theory- practice gap and the evidence-based practice movement to have increased the uptake and focus of action research in health and social care settings. The value of action research in health-related fields lies in the ability of the research process to enable researchers and practitioners to address problems faced in practice (Hart and Bond, 1995). Healthcare practitioners frustrated by the failure of research to provide solutions to workplace problems, use action research as its over-arching aim is to improve professional practice and raise the standards of service provision (Morton-Copper, 2000). In their systematic review, Waterman et al. (2001) also found that 'a real-world' focus, was highly important for researchers, with a majority of the projects embedded in practice settings.

In health and social care, action research has been used in a variety of ways and settings such as to improve service delivery within the community (Wilkinson, Elander and Woolaway, 1997), to initiate self-medication on a ward for elderly care (Webb et al., 1990), to describe the developmental and training needs of the registered nurses to become clinical supervisors (Lee, 1996), management of continence for community-dwelling women living with multiple sclerosis (Koch, Selim and Kralik, 2002) and evaluation of a community-based initiative aimed at preventing the spread of HIV amongst injecting drug users (Power, Dale and Jones, 1991). These examples demonstrate that action research can be applied to a wide range of health and social care settings.

4.8.1 Action research in stroke settings

It is useful to consider examples of action research studies within stroke research as stroke service users and providers are the target population in this study. In the UK, Kilbride et al. (2005) undertook an action research study over a two-year period at a large NHS teaching hospital with the aim of improving stroke services. They utilised mixed methods (audits, focus groups, in-depth interviews, documentary analysis, participant observation and field notes) with a total of 74 members of the multi-professional stroke team, hospital management team and representatives of patients and caregivers. Prior to the commencement of the study, stroke care was fragmented and uncoordinated; national audit results showed that there was room for improvement. Over the course of the study, stroke care improved markedly within the hospital, with death rates falling from 24% in the first year to 15% two years later. Although it may not be possible to directly attribute the falling death rates to the project, the authors highlight interrelated factors that arose from the action research cycles that contributed to the positive changes achieved. These include: building a team, sharing practice-based knowledge and skills, valuing the central role of the nurse and creating an organisational climate for supporting change (Kilbride et al., 2005).

Similarly, Allison et al. (2008) in South West England, successfully utilised an action research approach with a total of 38 participants (25 stroke survivors who had been discharged from hospital and 13 family caregivers) to explore their experiences of receiving secondary prevention advice; the findings were used to inform the development of an educational resource for secondary prevention of stroke. The result was a robust resource for secondary prevention education to be used in clinical

practice that is meaningful to patients and caregivers.

In North America, Hammel et al. (2006) utilised a participatory action research approach with 20 stroke survivors and their significant others (e.g. family, friends, caregivers) to identify community participation goals, barriers and supports to community living and participation. With the assistance of significant others, participants were involved in the planning of the study as well as data collection, in the forms of observations, goal-setting, environmental audits, field notes, digital pictures and photographs. Items for the participation barriers and supports checklist were generated from this data. This resulted in the creation of a participation checklist which now serves as the foundation for a web-based assessment tool for use by people with disabilities, community organisations, business and policy-makers to document barriers and strategise participation opportunities (Hammel et al., 2006). Clearly, action research is a successful approach within this clinical area and thus supports the selection of action research for this study involving family caregivers of stroke survivors and healthcare professionals working with people affected by stroke.

4.9 Justification for adopting action research in this study

Action research was specifically chosen as the ideal approach for this study because gaps were identified in the service provision for stroke family caregivers and there was an urgent need to improve practice (Meyer and Cooper, 2015). Additionally, the preliminary literature review that was conducted as part of this study revealed that short screening tools for use with the family caregivers of stroke survivors are currently lacking.

Furthermore, in action research, the approach involves doing research with and for people (service users) in the context of its application rather than undertaking research on them. This framework supports the overall aim of the study, which was not only to describe the experiences of the stroke family caregivers of the factors contributing to burden during caring post stroke, but to also work with them as well as service providers to change, develop and evaluate care practices by adapting the CAT to develop the CAT-S. The aim was to develop something tangible and meaningful to the stroke family caregivers as well as the service providers since they themselves helped to generate and make sense of the findings (Koshy, Koshy and Waterman, 2010).

The selection of an action research methodology is recognised as being an approach that, when developed in practice, is more likely to be suitable for the clinical and organisational needs and can therefore result in a quicker adoption of change into routine care and impact on family caregivers (Waterman et al., 2001; Munn-Giddings and Winter, 2013; Meyer and Cooper, 2015). This was evident from the consultation exercise conducted prior to the commencement of the study, with stroke family caregivers as well as service providers agreeing that identifying and providing support for stroke family caregivers was an area that required further exploration and improvement. Subsequently, it was easier to engage both service users as well as providers to take part in this study. Action research offered an ideal framework for changing practice and sustaining long- term impact by encouraging participants to take responsibility to work together to solve their own problems (McNiff and Whitehead, 2011; Munn-Giddings and Winter, 2013). The partnership between researchers and participants facilitates double loop learning as opposed to single loop learning (Argyris,

2006) to occur. In single loop learning problems are addressed whilst holding on to existing values, attitudes and norms. In contrast, double loop learning takes place when underlying core values, norms and attitudes are altered thus enabling sustainable change to take place (Argyris, 2006; Hynes, 2013). The length of the sustainability of changes however, varies depending on the context and focus of the project (Waterman et al., 2001). Nonetheless, the cyclical nature of action research provides an opportunity to continue monitoring changes and exploring further action to sustain the changes (Waterman et al., 2001; Meyer and Copper, 2015). This notion of continued inquiry is central to sustainability in action research studies (Hynes, 2013). The next section will explain the action research process that was adopted in this study.

4.10 The action research process

The action research process described by Meyer (2010) will be explored in this section to provide a rationale of the study phases that were followed. This approach is characterised by three phases namely exploratory, intervention and evaluation (Meyer, 2010).

According to Meyer (2010), these phases are common with all action research projects. Within the different phases, there are action research spirals or cycles involving planning, acting, observing, reflecting and re-planning aspects (McNiff, 1988). Although different action research projects use the cycles of action in different phases of the research, the rationale underpinning them remains the same (Drummond and Themessl-Huber, 2007). In reality, the phases somewhat overlap and

thus reflect the nature of action research allowing the researcher to flexibly respond to dynamic changes occurring in reality (Meyer, 1993). The activities that were undertaken in each phase will be described next. For ease of description, the study is presented in distinct phases. By way of illustration and to aid with understanding of the action research phases, the current study has been described with full details of methods of data collection and justifications provided in Chapter 5 (Methods).

4.10.1 Pre-exploratory phase (consultation exercise)

Prior to the commencement of this study, an initial consultation exercise was undertaken between April 2015 to May 2015 with approximately 29 key stakeholders comprising stroke family caregivers, community-based stroke coordinators, managers from a national charity that supports individuals affected by stroke, staff working at a stroke charity (TLC stroke project), stroke unit doctors, therapists and stroke nurses in London and the North-West of England.

Three face-to-face meetings were held: one on a stroke unit in London attended by nine stroke family caregivers and seven stroke unit staff, while two further meetings were undertaken in Lancashire with four community-based stroke coordinators and three managers from a national charity as mentioned previously. Additionally, multiple telephone conversations, face-to-face conversations and email communications were also undertaken with stroke family caregivers and various health and social care professionals working with people affected by stroke such as stroke occupational therapists, physiotherapists and carer support specialists.

The consultation exercise was carried out in order to explore and discuss the focus and validate the value of the study. Involving key stakeholders prior to the commencement of the study supports action research which aims to explore the experiences of people within their specific social environments, so that the nature of the problem can be described within the context of the field to which it belongs (Stringer, 1996). It was evident from the feedback received that identifying and supporting the needs of stroke family caregivers was an area that required immediate improvement. During this period, some stakeholders shared assessment forms that are used in practice; it also became apparent that there were a lot of variations in the assessments available to stroke family caregivers. Consultation with key stakeholders continued throughout the duration of the study.

4.10.2 Exploratory phase

In the exploratory phase, data is collected in order to explore the nature of the problem and focus of the study (Meyer, 2010). As stated earlier in this chapter, details and justifications of the data collection methods are reported in Chapter 5. Nonetheless, formation of an action research group, two narrative literature reviews, semi-structured interviews and a modified Delphi survey were the activities that were undertaken as part of this phase.

Formation of a virtual action research group

In order to fulfil the criteria of action research, an action research group was set up (Kemmis and McTaggart, 1988). The researcher must create opportunities to engage with stakeholders in a manner that upholds democratic values and a willingness to

discover knowledge together (Greenwood and Levin, 2006). Predominantly, the researcher takes on the role of facilitator, coordinating the research process while allowing the community to direct progress towards outcomes (Meyer, 2010). This study was undertaken as part of an academic degree; therefore, a pragmatic approach was adopted resulting in the formation of a virtual action research group (VAG) due to time and resource constraints. Details of the VAG are provided in Chapter 5.

Review of the literature

As part of the exploratory phase, two literature reviews were undertaken as described in Chapters 2 and 3. The first literature review highlighted the numerous challenges that are experienced by family caregivers when supporting individuals following a stroke. Furthermore, the findings enabled multiple facets of the family caregivers' experiences to be considered for inclusion in the CAT-S. A notable finding in the second literature review was the lack of stroke specific tools for use in clinical practice and also the lack of information on the experiences of personnel when administering these tools. This further reinforced the need to conduct this study. The results of the two literature reviews were shared with members of the VAG.

Experiences of stroke family caregivers and their views regarding the original CAT

In order to explore stroke family caregivers' experiences of the factors contributing to burden during caring post stroke and also to seek their views regarding the original CAT, a qualitative approach was considered appropriate to enable the exploration of the participants' experiences, feelings and beliefs (Holloway and Wheeler, 2010; Polit and Beck, 2017). Semi-structured interviews (Gray, 2014) were completed as part of

this phase. Prior to the interviews, an interview guide was developed and circulated to all members of the VAG for comments. Chapter 5 (section 5.6.1) contains details of the semi- structured interviews that were conducted.

CAT-S item generation and selection

Using the themes generated from the semi-structured interviews and the two literature reviews (Chapter 2 and 3), a questionnaire was devised and shared with members of the VAG for their comments before it was piloted. Additional consultation and engagement with stakeholders including stroke family caregivers, stroke nurses and other health and social care professionals working with people affected by stroke took place through a modified Delphi survey (Hasson, Keeney and McKenna, 2000). These involved participants ranking and rating the items to be included in the CAT-S. Details of the two-round modified Delphi survey are presented in Chapter 5 (section 5.7.1).

Drawing upon the development of the initial CAT (Knighting et al., 2015), further consultation on the items to be included in the CAT-S took place with an expert panel of 11 members (stroke family caregivers n=6 and staff from a national charity n=5). Their comments were shared with the VAG and necessary amendments were made. Ten of the highest ranked items from the modified Delphi survey and two items which were not highly ranked but viewed to be important by the VAG following a final review of the evidence, were included in the CAT-S (Table 34, Chapter 7).

4.10.3 Intervention phase

In this phase, a number of action research cycles usually emerge as spirals of activity

(Meyer, 2010). It involves implementing the proposed action in practice and represents an opportunity to pursue 'ideas in practice' (Kemmis and McTaggart, 1982). The purpose of action is to improve a situation, benefit practice and extend knowledge (Carr and Kemmis, 1986). The implementation phase in this study involved developing and piloting the CAT-S with stroke family caregivers and community-based stroke coordinators.

CAT-S Pilot

Through the cooperation of the community stroke coordinators, the CAT-S was piloted with five family caregivers and four community-based stroke coordinators. During home visits, the community stroke coordinator completed the CAT-S with the stroke family caregivers who consented to take part. All materials used in the CAT-S pilot were shared with the VAG before use for their input and comments. The findings from the CAT-S pilot are presented in Chapter 8. Staff from a national charity assisted in updating the suggested 'next steps' section of the pilot CAT-S in order to reflect the local services and support available before it was piloted. Details of the processes that were followed to recruit participants to the small pilot study are presented in Chapter 5.

4.10.4 Evaluation phase

This phase evaluates the actions and processes that have been taken and enable conclusions to be made regarding whether or not the actions have resulted in any change or improvements (Meyer, 2010). Experiences of stroke family caregivers and community-based stroke coordinators when using the CAT-S were sought in this

phase. As stated earlier in this chapter, the phases of action research overlap in reality (Meyer, 1993). In the current study, although the staff feedback forms were completed during the CAT-S pilot (intervention phase), they formed part of the evaluation phase. The aim was to understand how usable and comprehensive the CAT-S is for staff by reviewing the feedback forms completed as part of the pilot by the community- based stroke coordinators. Additionally, semi-structured interviews (Gray, 2014) with stroke family caregivers were conducted to explore their experiences when using the CAT-S. The goal was to establish the usability of the CAT-S such as whether the CAT-S took a reasonable amount of time to complete, any identified alerts and whether this resulted in any additional help. A content analysis approach (Elo and Kyngas, 2008) was used to analyse the data collected from the semi-structured interviews and the findings were shared with the participants and also members of the VAG. Full details of the content analysis are provided in Chapter 5 (5.9.3).

It is argued by Meyer (2010) that there is no neat end to an action research project as action researchers often wish to continue with the change process. Nevertheless, action researchers need to withdraw from the field to analyse and reflect on what has been learnt in the context of the wider body of knowledge (Meyer, 2010). After the findings from the staff feedback forms and semi-structured interviews were summarised and discussed with members of the VAG, the group was dissolved, and the researcher withdrew from the field. However, communication was maintained with four members of the group for further collaborative work. The next section will discuss the challenges in action research studies.

4.11 Challenges with action research

In action research, the partnership between the researcher and stakeholders is a key element (Waterman et al., 2001; Meyer, 2010). However, engaging in research based on a partnership model has its own difficulties. In order to undertake action research effectively, the researcher must have the ability to collaborate and take on the role of a facilitator. If the researcher encounters difficulty in building relationships and undertaking the facilitator's role, the methodology will be limited in its capacity for benefit (Waterman, 2007). During the consultation period, time was spent visiting local stroke services and building relationships that proved to be worthwhile during the recruitment of participants to the study as well as identifying members of the VAG. Additionally, findings from all the phases of this study were shared with members of the VAG in order to promote ownership of the project and subsequently allow for the rapid uptake of the proposed changes and adoption of the CAT-S in practice (Waterman et al., 2001).

Action research is undertaken in real situations and therefore has the potential to become unruly and unpredictable (Hart and Bond, 1995; Stringer, 1996). It can be difficult for participants to know what they are signing up to and fully understand the potential implications of the work to be undertaken. Although at the onset of the project, the general area of investigation can be agreed, issues that arise can be both unexpected and potentially unwelcome and the actions taken not what was originally anticipated. The actions taken to address these challenges can include highlighting the uncertainty of the action research process to participants at the onset of the project (Meyer, 1993). These potential challenges were highlighted to members of the VAG

immediately after joining the group. Another challenge pertaining to action research reported in the literature is the significant amount of time taken to complete action research projects (Meyer, 1993; Waterman et al., 2001; Hockley and Froggatt, 2006). Awareness of this challenge has enabled the adoption of a flexible approach to action research through the creation of the VAG. The next section will explore the criteria for assessing quality in action research.

4.12. Criteria for assessing quality in action research

In the literature, there is debate about the different components that should be included when measuring the quality of an action research study (Waterman et al., 2001; Koshy, Koshy and Waterman, 2010). Some authors disagree with having an evaluative criterion as action research projects are unique and very contextually-based (Koch and Kralik, 2006; Reason and Bradbury, 2006). The whole process may also be viewed as the opposite of the democratic principles of action research (Reason and Bradbury, 2006).

The current interest in evidence-based practice, however, has resulted in research projects receiving much scrutiny for their quality and application to practice. Action research must, therefore, be open to evaluation if it is to be considered as evidence for practice (Williamson, Bellman and Webster, 2012). Unless guidance is offered, action research may be assessed according to criteria designed for use with other research methodologies, e.g. through issues of validity and reliability as is the case with positivist research (Badger, 2000). Consequently, action research can be misunderstood or even dismissed (Waterman et al., 2001; Williamson, Bellman and

Webster, 2012). Evaluative criteria are therefore necessary for the sake of clarity and also to encourage reporting standards in journals. It also encourages novice action researchers to achieve high standards (Waterman et al., 2001). These criteria can also serve the needs of other stakeholders such as funding bodies, practitioners, students and supervisors as well as critics, thus allowing them to have a shared understanding of the quality of action research projects and reports (Williamson, Bellman and Webster, 2012).

Various authors offer different components that must be included when measuring the quality of action research. Herr and Anderson (2005) offer five goals which include: generation of new knowledge, achievement of action- oriented outcomes, education of the researcher and participants, results that are relevant to the local setting and appropriate methodology. Similarly, Gomm, Needham and Bullman (2000) present five questions for evaluating the quality of action research and their ideas include: evidence of change, replicability, experiment effect, biased reporting and understanding.

Additionally, Koch and Kralik (2006) also discuss rigour and quality in action research. They argue that there are sufficient rules-based approaches to rigour within traditional research methodologies and that, what is important in action research is whether it is accessible, makes a difference and is sustainable. They present seven questions for consideration regarding the rigour of action research (Figure 5)

Figure 5: Koch and Kralik's questions regarding rigour (Koch and Kralik, 2006)

- What is the world view?
- Is the inquiry credible?
- Is the inquiry transferable?
- Is the study dependable?
- Is the study believable?
- What values and interests do researchers bring to the inquiry?
- Is the work accessible?

Furthermore, Williamson, Bellman and Webster (2012) collated and reviewed a number of different approaches taken to assess the quality of action research. They reviewed the criterion presented by Gomm, Needham and Bullman (2000), Waterman et al. (2001), Herr and Anderson (2005), Reason and Bradbury, (2006), Koch and Kralik (2006). They identified five key areas of similarity in the authors' ideas of evaluating the quality of action research and developed their own criteria from this (Figure 6). However, Williamson (2012) cautions that although reasonably detailed, all the suggested criteria by the different authors, including their own, can never fully do justice to the complexity and context-bound nature of an action research study. They must, therefore, be viewed as a 'broad brush' approach to the evaluation of action research projects (Williamson, Bellman and Webster, 2012).

Figure 6: Five key areas of similarity in authors' ideas of evaluating the quality of action research (Williamson, Bellman and Webster, 2012).

1) Generate new knowledge
2) Produce change
3) Have an ethic of participation
4) Demonstrate rigorous methods of inquiry
5) Transferable

When considering how to measure the quality of this action research project, the criteria suggested by Koch and Kralik (2006) were selected. The choice was guided by the overall aim of this study which was to adapt the CAT and develop the CAT-S for use with stroke family caregivers. Unlike other criteria mentioned in this chapter, which place their emphasis on change, the criteria by Koch and Kralik (2006) place an emphasis on participation. In Chapter 10 of this thesis, a discussion of how the criteria of Koch and Kralik (2006) was applied to assess the quality of this study is provided.

4.13 Chapter summary

In this chapter, the key components of action research and its different approaches have been highlighted. The processes that were followed have also been described using the framework by Meyer (2010). Finally, the criteria for assessing quality in action research were discussed. The next chapter will outline the study phases before discussing the methods adopted throughout this study for participant recruitment, data collection and data analysis.

Chapter 5: Methods

5.1 Introduction

The previous chapter explored the methodology that was adopted to conduct the current study. This study was underpinned by principles of action research and also informed by the literature on instrument development. In this chapter the objectives of the study in relation to the action research phases described in Chapter 4 are presented. This is followed by the ethical considerations that were adhered to during the course of the study. The various data collection and data analysis strategies that were utilised in each phase of the study are described and the rationale for their choice is provided to enhance the rigour of the study.

5.2 Research aim

The overall aim of this study was to adapt the CAT and develop the CAT-S specifically for use with family caregivers of stroke survivors. Collaboration with key stakeholders such as the family caregivers of stroke survivors and staff working within stroke services through action research was considered an ideal approach as gaps were identified in the service provision for the family caregivers of stroke survivors (Waterman et al., 2001; Meyer, 2010). The strength of action research lies in its focus to generate solutions to practical problems and its ability to empower practitioners, getting them to engage with research and the subsequent development or implementation of activities (Koshy, Koshy and Waterman, 2010; Meyer, 2010). The members of the virtual action research group (VAG) described later in this chapter were therefore consulted throughout the conduct of this study.

5.3 Study phases and objectives

This study comprises three inter-related phases of the action research cycle namely the exploratory, implementation and evaluation phase (Meyer, 2010). Nevertheless, each phase had its own objectives and different data collection methods were employed to achieve the study objectives. Data were collected and analysed sequentially in one phase to inform the next phase. Table 11 provides an overview of the different phases of the study, the objectives for each phase and the data collection strategies utilised. In Table 12 an overview the activities in each phase and the modes of participation by the participants is presented. During the course of the study, a personal diary was maintained where all events that occurred and decision made were recorded to enhance transparency of the process (Denscombe, 2014).

Table 11: Overview of the study objectives and the data collection methods used

Research phase and dates	Study objectives	Data collection method
Exploratory phase Part one: February -May 2016)	Part one Objective 1: To explore the experiences of stroke family caregivers of factors contributing to burden when providing care to individuals following stroke. Objective 2: To seek the views of the stroke family caregivers about the CAT	Semi-structured interviews with stroke family caregivers in North West England Semi-structured interviews with stroke family caregivers in North West England
Part two: Round 1 (February - April 2017) Round 2 (May - July 2017)	Part two Objective 3: To gain consensus from stroke family caregivers and staff working within stroke services on the most important items to be included in the CAT-S	Two round modified Delphi surveys (two cohorts) stroke family caregivers and staff working within stroke services across the UK Consultation with an expert panel (comprising of VAG members as presented in Chapter 4, and three stroke family caregivers who participated in part one of this phase). Short questionnaire used to collect data
Implementation phase October - November 2017	Objective 4: To pilot the CAT-S to test feasibility of recruitment, methods of data collection, its usability and usefulness in practice to identify stroke family caregivers needs for those supporting stroke survivors.	Pilot CAT-S completed with stroke family caregivers by community- based stroke coordinators in North West England. Staff feedback forms completed as part of the pilot.
Evaluation phase October - December 2017	Objective 5: To explore the experiences of stroke family caregivers and community-based stroke coordinators when using the CAT-S	Semi-structured interviews with stroke family caregivers in North West England. Staff feedback forms that were completed as part of the CAT-S pilot.

Table 12: Overview of study phases, activities, participants and type of participation within the study phases

Research Phase and dates	Activities	Participants	Participation
Pre- exploratory phase (April 2015 - May 2015)	Consultation exercise	Research student with key stakeholders i.e. stroke family caregivers, community-based stroke coordinators, managers from a national stroke charity, staff working at a stroke charity, stroke unit doctors, therapists and stroke nurses.	Consultation
Exploratory phase (September 2015)	Formation of the 'CAT-S virtual advisory group' (VAG)	Stroke family caregiver, stroke consultant, community stroke physiotherapist, managers from a national stroke charity, community- based stroke coordinators	Co-learning
(February -May 2016)	Semi-structured interviews with stroke family caregivers	Research student (interview guide and results discussed with the VAG).	Co-learning
Round 1 and Round 2 (February - July 2017)	CAT-S item selection (Delphi survey)	Stroke family caregivers, healthcare professionals working with stroke survivors and their families. Contents of Delphi discussed with the VAG	Consultation Co-learning Cooperation
Implementation phase (October - November 2017)	Action cycle CAT-S pilot	Community-based stroke coordinators and stroke family caregivers. Pilot materials discussed with the VAG	Cooperation Co-learning
Evaluation phase (October -December 2017)	Feedback forms Semi-structured interviews	Researcher (Questions on feedback forms, interview guides and results discussed with VAG)	Co-learning

5.4 Ethical considerations

5.4.1 Ethical approvals

Before any research involving humans is undertaken, approval from an appropriate Research Ethics Committee is required to ensure that participants are respected and protected and that the study being undertaken has potential benefits (Gray, 2014; Johnson and Long, 2015; Silverman, 2017). Prior to the commencement of data collection in each phase of this study, ethical approval was sought and received from Edge Hill University Faculty of Health and Social Care Research Ethics Committee (FREC) (Appendices 8-10). Ethical approvals were sought separately for each phase to allow 'democratic collaboration' between the research student and the members of the VAG consisting of information sharing, systematic inquiry, reflection and action which are key in action research (McNiff, 1998). Furthermore, it was impossible to provide the Ethics Committee with explicit details and supporting documents of all the subsequent phases in advance without prior consultation with the VAG members as the data collected in one phase of this study informed the next phase. Additionally, permission was sought and obtained from the research office of a national charity that supports individuals affected by stroke to conduct the study at three of their centres in North West of England and also to advertise the Delphi survey on a section of their website.

5.4.2 Voluntary participation and informed consent

Participation in research must always be voluntary and sufficient information is required to enable people to make decisions about participating in a study (Saks and

Allsop, 2007; Polit and Beck, 2017). Participant information sheets were therefore provided to all potential participants prior to recruitment in all the phases of this study. The information sheets described the purpose of the study, the procedures to be followed, risks and benefits of participation and how the data collected would be utilised. An example of a participant information sheet is provided in Appendix 11. Furthermore, the participant information sheets contained the contact details of the research team in case the participants required clarifications before deciding to take part. Participation was voluntary in all the phases of the study. Details of the processes involved in each phase are described under each individual phase within this Chapter.

For semi-structured interviews, written consent (Appendix 12) was obtained upon arrival at the interview location, prior to the commencement of data collection for participants who took part in the interviews during the exploratory and evaluation phases of the study. Allowing participants to sign consent forms provides respondents the opportunity to be fully informed of the nature of the research and the implications of their participation in the study; it also indicates that informed consent has been given (Tod, 2015; Bryman, 2016). Implied consent (Jones and Rattray, 2015) was assumed upon completion of the modified Delphi survey by the participants (Keeney, 2015).

5.4.3 Protecting participants from harm

Protecting individuals from harm is a key feature of ethical research. Harm can embrace a variety of issues ranging from physical, mental and emotional harm (Sudman, 1998; Gray, 2014). In most instances, the risk of psychological or emotional harm can be less obvious than the risk of physical harm and as a result, researchers

need to pay attention in this area (Webster, Lewis and Brown, 2014; Silverman, 2017). In this study, it was recognised that there was potential for conversations during interviews or when responding to survey questions for the caregivers to experience some emotional stress. With this in mind, participant information sheets contained information of the potential risks of participation to enable participants to decide whether or not they wished to take part. Prior to the interviews, participants were reminded that they could either take a break or terminate the interview at any time. Furthermore, family caregivers who participated in the various phases of the study were all provided with information of the support services available to family caregivers to enable them to seek support where necessary (Bryman, 2016; Polit and Beck, 2017).

5.4.4 Confidentiality and anonymity of study participants

The right to anonymity and confidentiality of the study participants is another fundamental principle of ethical research (Burns, Grove and Gray, 2011; Webster, Lewis and Brown, 2014; Nursing and Midwifery Council (NMC), 2018). To ensure confidentiality throughout this study, data from all interviews were transcribed verbatim and anonymised by removing any identifiable data and replacing names with pseudonyms. The audio-files of the interviews were stored electronically on the University's secure password protected server. The Delphi survey was anonymous, however, all hardcopies of data including the completed paper survey, signed consent forms and transcripts were stored in a lockable research office within the University premises. All research files were only accessible to the research student and the supervisory team. Upon completion of the study, all research data will be kept stored

for 10 years and destroyed afterwards in compliance with the Data Protection Act (2018) (Great Britain Parliament, 2018) and the Edge Hill University Research Data Management Guidelines. The next section will present the data collection strategies utilised in this study. As presented in Section 5.3 of this chapter (Table 11), various data collection techniques were used to gather data sequentially in the different phases of this study. Therefore, to aid with explanation and offer clarity, each phase will be presented separately together with the data collection methods utilised.

5.5 Formation of VAG

As stated previously Chapter 4 (section 4.10.2), a virtual action research group (VAG) was created at the commencement of this study in September 2015. All communication and discussions were virtual via electronic communication. This pragmatic approach enabled a wide range of stakeholders to be involved in the process from a wider geographical area, thus allowing input from different areas rather than individual local views. Furthermore, this adds to the transferability of findings. The establishment of an action research group meets the fundamental aim of ensuring that people work together to identify and reflect on issues with the intention of taking strategically informed action (Kemmis and McTaggart, 1982). The composition of the group included representatives from various key stakeholders. Table 13 provides a summary of the roles of the action research group members and their geographical location. Members of the action research group were selected because it was felt that they would provide valuable insight and contribute positively to the development of the CAT-S and its potential use in practice. The role of the research student was an integrated member of the group regarding decision-making and to collect information

from the discussions and also provide theoretical expertise and facilitate group dynamics.

Table 13 : Composition of the virtual action research group

Role	Location	Number
Stroke family caregivers	Liverpool	3
Managers from a national stroke charity	Preston, Southport, Aintree (one at each site)	3
Stroke consultant (medical doctor)	London	1
Community stroke physiotherapist	London	1
Community-based stroke coordinators	(Southport and Preston)	2

The virtual action research group was created on 'Wikki' - an online discussion platform following consultations with the University Information and Technology team and the supervisory team. The group was named 'CAT-S virtual advisory group' (VAG). Potential members were approached prior to setting up the group either via email, telephone or in person. The purpose of the group and expectations were explained. An invitation email was sent out to all potential members requesting them to accept the invitation by clicking the 'join group' button, which was contained in the invitation email; all responded and joined the group. Furthermore, guidance was sought from the supervisory team and a senior member of staff within the faculty, who has an added responsibility of integrating learning and technology. Group guidelines for VAG members regarding their role within the group were developed and uploaded on the 'CAT-S VAG' for all members to read (Appendix 13).

The main role of the VAG was to provide suggestions and guidance on the development of the CAT-S and its potential use in practice. The degree of their participation varied throughout the study as illustrated in Table 12. All members were consulted prior to the start of each data collection phase and the results of each phase were shared with them, thus allowing reflection and co-learning to take place amongst the group members. It is important to note that although initially the VAG consisted of one family caregiver, two family caregivers were invited to join the group in October 2017 following the feedback received during the progression viva. This was done to increase the representation of stroke family caregivers on the VAG and complements the cyclical nature of the action research methodology where amendments can be made following the feedback received (Waterman et al., 2001; Meyer, 2010).

5.6 Exploratory phase: part one

The exploratory phase consisted of two parts. The first part had two objectives: to explore the experiences of stroke family caregivers of factors contributing to burden when providing care to stroke survivors and to determine their views about the CAT. Semi-structured interviews were therefore utilised to collect data and achieve the objectives of this phase between February - May 2016. Findings from the semi-structured interviews contributed to the development of the survey that was conducted in the second part of the exploratory phase.

The second part of the exploratory phase aimed to gain consensus from stroke family caregivers and staff working within stroke services on the most important items to be included in the CAT-S. This was achieved through a modified Delphi survey (Keeney,

Hasson and McKenna, 2011) followed by a consultation with an expert panel. Full details of the modified Delphi survey are presented later in this chapter (section 5.7). The techniques and the processes that were followed to collect data in the two parts of the exploratory phase will now be presented.

5.6.1 Semi-structured interviews

During the first part of the exploratory phase, focus group interviews and semi-structured interviews were initially planned to explore family caregivers' experiences of factors contributing to burden when supporting individuals following a stroke and also to seek their views about the CAT. Interviews are commonly used in qualitative research to elicit information from participants and discover the informant's experiences, feelings, perceptions and thoughts (Holloway and Wheeler, 2010; Patton, 2013; Tod, 2015). Focus group interviews were deemed appropriate as they promote group discussion and debate (Krueger, 1994; Kitzinger, 1995). Additionally, they are efficient as a data collection strategy since researchers are able to obtain the viewpoints of many individuals in a short period of time (Krueger, 1994; Polit and Beck, 2017). However, although focus group interviews were initially planned, staffing problems at two data collection sites resulted in difficulties with the recruitment of caregivers via the carer support groups and subsequently, only semi-structured interviews were conducted to achieve the first two objectives of this study.

Semi-structured interviews involve the use of pre-determined questions (topic guide) and the researcher is free to seek clarifications (Parahoo, 2006; Rubin and Rubin 2012; Gray, 2014). They were considered ideal for this study because they allow

researchers to address themes that are relevant to the research questions whilst allowing participants to talk freely about their experiences (Britten, 2006; Polit and Beck, 2017). However, one limitation with all types of interviews including semi-structured interviews is that they can be expensive in terms of time and transportation to arrive at the interview location (Denscombe, 2014; Tod, 2015).

A topic guide (Holloway and Wheeler, 2010) was developed and used to conduct the semi-structured interviews. This ensured that all participants were questioned about the same topics (Holloway and Wheler, 2010; Green and Thorogood, 2018). The topics included on the guide were regarding the family caregivers current caring role, the support and assessments they had received and the appropriateness of the items on the CAT-S. Additionally, participants were asked to provide demographic information. Questions included in the topic guide originated from the aim and objectives of the study, the literature on the experiences of the family caregivers of stroke survivors as well as the items on the CAT (Appendix 14). A draft of the interview guide was shared and discussed with members of the supervisory team. This was then circulated to all members of the VAG. Members were asked to comment on the appropriateness of the topics and also to identify any missing topic areas. They were given seven days as agreed at the formation of the VAG to provide their comments, such as any missing questions or if any questions needed to be removed. No changes were suggested by the group.

Pilot

Before conducting the interviews, a pilot of the interview guide was undertaken with

two family caregivers of stroke survivors (Arthur et al., 2014; Lacey, 2015). One was a member of the VAG and the other a caregiver who is personally known to the research student. The aim of this pilot was to establish the clarity of the questions, assess the interviewer's use of the guide and the quality of the data obtained. Following the pilot, the phrasing on some of the questions was altered prior to the start of the interviews to ensure their clarity.

5.6.2 Participants

The target population for the semi-structured interviews were family caregivers who were supporting stroke survivors residing at home. A purposive sampling technique which focuses on the conscious selection of certain subjects believed to be knowledgeable about the issues under study was adopted (Creswell, 2013; Hunt and Lathlean, 2015). It involves applying specific criteria to ensure that the selected sample are able to answer questions relating to the phenomenon being researched. The inclusion criteria for the semi-structured interviews were:

- Family caregivers of stroke survivors aged over 18.
- Family caregivers residing at the same address with the stroke survivor.
- English-speaking family caregivers.

Family caregivers under 18 years of age, voluntary or paid caregivers, as well as family caregivers not living at the same address with the stroke survivor, e.g. those with stroke survivors in residential or nursing homes were specifically excluded as they may possibly have different needs compared to family caregivers residing together with the stroke survivor (Becker, 2007). Non-English-speaking family caregivers were

also excluded.

The sample strategy for this phase was to recruit participants in order to achieve data saturation. This is when no new information is obtained from participants (Polit and Beck, 2017). Disagreement exists in the literature as to the number of participants required to reach saturation (Fusch and Ness, 2015). An initial sample of 20 participants was considered sufficient to address the first two objectives of this study with the possibility to increase the sample size if felt necessary (Hunt and Lathlean, 2015). Data saturation was reached after interviewing 16 family caregivers who fulfilled the inclusion criteria during this phase of the study.

5.6.3 Access to research sites

The research sites for part one of the exploratory phase involved three sites of a national stroke charity in North West of England. To gain access and entry to the research sites, researchers must negotiate with 'gatekeepers' - people who have the power to grant or withhold access to the setting (Holloway and Wheeler, 2010; Gelling, 2015). Permission was therefore sought from the Regional Manager and Managers at the three sites of the charity. No further approvals were required from the national charity; however, a copy of the ethical approval letter from the University's FREC was shared with the Regional Manager and the centre Managers at the three sites. The consultation exercise conducted in the pre-exploratory phase of this study, as described in the methodology chapter (Chapter 4), as well as having the centre Mangers as members of the VAG facilitated access at the three sites as most gatekeepers were already aware of the study.

5.6.4 Recruitment

An invitation letter (Appendix 15) and participant information sheets were distributed to the three sites as stated above. The community-based stroke coordinators were asked to hand these out to family caregivers when conducting home visits. Potential participants were then encouraged to contact the research team to ask any questions or arrange an interview. However, following feedback from the stroke coordinators, the recruitment strategy was amended. The proposed change was to allow the coordinators to pass the details of the family caregivers to the research team following consent from the family caregivers. This strategy aimed at boosting recruitment considering the demanding schedules of most family caregivers. Authorisation of the amendments was granted by the acting chair of the University's FREC in February 2016. This proved to be worthwhile as seven new participants were recruited into the study.

Additionally, meetings were arranged at two of the research sites via support groups for stroke family caregivers. The study aims and objectives were explained and an opportunity was offered to family caregivers to ask any questions. Study information packs containing an invitation letter and the participant information sheet were handed out to family caregivers. Potential participants were asked to provide their name and contact details if they were willing to be contacted to arrange an interview. The contact numbers of the research team were included on both the invitation letter and the information sheets to allow potential participants to ask any questions. Those who wished to be contacted were then contacted 24 hours after the initial meeting to establish if they were still interested in participating. The interview dates, time and

venue were arranged with those wishing to participate. A total of 26 potential participants were identified either through the community-based stroke coordinators or the carer support groups and 21 met the inclusion criteria but five were excluded. Three were not living at the same address with the stroke survivor, one was a paid caregiver and one was bereaved before an interview was arranged. Out of the 21 potential participants, 16 stroke family caregivers agreed to take part and were interviewed between February and May 2016.

5.6.5 Conducting the interviews

All interviews were conducted face-to-face by the research student. Prior to the start of the interview, potential participants were asked to read and sign a consent form. The participants were invited to respond to several questions, both open and closed. They were also asked information about their demographic details including their age, employment status, gender, their relationship with the stroke survivor and ethnicity. Furthermore, they were asked to provide some information about the individual who they were supporting, in particular how they were affected by the stroke and their dependence on the family caregivers in performing activities of daily living, such as meeting their personal hygiene needs, mobility, eating and drinking and elimination. From this information, the interviewer utilised her clinical judgement as a Clinical Nurse Specialist for stroke to establish the level of disability of the stroke survivor. The Modified Rankin Scale (MRS) (Van Swieten et al., 1988) (Appendix 16), one of the most widely used measures in stroke assessment, was used (Huybrechts, 2007). Individuals can score a minimum of zero or a maximum of six on the MRS. A higher reading on the MRS indicates greater disability. This information was deemed

necessary because a stroke is a heterogeneous condition which can affect people in different ways.

As described earlier in this chapter, participants were invited to respond to open-ended questions concerning their caregiving role and assessments received. In order to achieve the second objective of this study, participants were shown the original CAT. Questions on the original CAT were regarding the family caregivers caring situation and their own health and well-being (See Appendix 1 for the original CAT). Participants were invited to comment on the appropriateness of the questions on the CAT. They were also asked to identify any questions or items that they felt were missing from the CAT in relation to their own personal experiences (Appendix 14). Each participant was interviewed once and alone.

Consistent with the semi-structured interviews, as described earlier in section 5.6.1 an interview guide was utilised, and this allowed probing and further inquiry in relation to the research questions (Holloway and Wheeler, 2010; Rubin and Rubin, 2012). Additionally, it served as a checklist to ensure that all relevant topics were covered (Patton, 2013). The sequencing of questions, however, differed across the interviews and the research student was guided by the participant's responses whilst taking into consideration the aim of the study.

The majority of the interviews were conducted at the participant's home; eight at home, five at the venues where a national charity ran their carer support groups; two in a café and one within the University offices as preferred by the participant. The length of the

interviews ranged between 35 and 55 minutes. All interviews were audio-recorded digitally once participant consent has been granted. Various ways of recording interviews include writing notes during the interview, notes written afterwards or audio- and video-recording (Pope and Mays, 2006; Polgar and Thomas, 2013). In this study, audio-recording was preferred as writing notes during the interview can interfere with the interview and notes written afterwards are likely to overlook interview details (Pope and Mays, 2006). Video-recording may also appear more intrusive and threatening to the participants (Polgar and Thomas, 2013). Most authors (Legard, Keegan and Ward, 2003; Patton, 2013; Silverman, 2017) in turn advocate for the audio-recording of interviews.

5.6.6 Data analysis

A thematic analysis approach was utilised to analyse data collected from the semi-structured interviews in the first part of the exploratory phase. Thematic analysis has been defined as ‘a method for identifying, analysing and reporting patterns (themes) within data’ (Braun and Clarke, 2006: 79). Boyatzis (1998:1) describes it as ‘a way of seeing’ where patterns are perceived, classified and interpreted. Thematic analysis is not tied to any particular discipline or set of theoretical constructs making it a widely used method (Ritchie et al., 2014). It was considered to be the most suitable for this study due to its flexible and pragmatic approach. Additionally, according to Pope, Ziebland and Mays (2006), thematic analysis is simple and easy to understand. Winter and Munn- Giddings (2001: 235) further advocate that ‘in action research projects, data analysis must not be so time consuming and elaborate that it distracts us from the collaborative and action-oriented progress of work’.

Computer-assisted qualitative data analysis software, NVivo version 11® (QSR International, 2015) was used to assist with organising and storing the data into folders for easy retrieval and further conduct of analysis (Ritchie et al., 2014). The six phases of thematic analysis advocated by Braun and Clarke (2006) were followed (Appendix 17). Firstly, data were transcribed verbatim into written form and checked for accuracy by listening to the audiotapes; this provided an opportunity to start familiarisation with the data. Transcripts were then read and re-read searching for the meaning of text in relation to the first research objective of this study and notes were made for future reference in subsequent phases (Boyzatis, 1998; Braun and Clarke, 2006).

The next phase involved the production of initial labels 'codes' where data were grouped in sub-themes (Braun and Clarke, 2006; Ritchie et al., 2014). This enabled data to be organised in meaningful groups (Tuckett, 2005). Searching for themes followed where the analysis re-focused to the broader level of themes rather than codes; involving sorting the different codes into potential themes and collating all relevant coded data extracts within identified themes (Braun and Clarke, 2006; Pope and Mays, 2006; Ritchie, et al., 2014). The themes were then reviewed and further refined, where the collated extracts of each theme is read and consideration is given to whether they appear to form a coherent pattern. The following phase involved defining and naming themes, identifying the essence of what each theme is about and determining what aspect of data each theme captures (Boyzatis, 1998; Braun and Clarke, 2006). The collated data extracts for each theme were then organised into a coherent and consistent account with accompanying narratives. The last stage involved the final analysis and write-up of the report findings, providing sufficient

evidence of the themes within the data as well as enough data extracts to demonstrate the prevalence of the theme (Braun and Clarke, 2006; Clarke and Braun, 2013). Two members of the supervisory team independently read half of the transcripts (n=8) to establish if they agreed with the data labels and the logical paths taken. This was done to enhance the credibility of the findings (Saks and Allsop, 2007; Silverman, 2017).

The focus of analysing data in action research is learning and implementing change unlike other forms of research where the focus is on description or constructing interpretations (Hart and Bond, 1995). The reflections on the data collected at one stage become data informing the next stage (Winter and Munn-Giddings, 2001). The emerging themes in this phase were important as they formed the content of the questionnaire for the second part of the exploratory phase. Appendix 18 provides an example of the themes and sub-themes that emerged from the data analysis. Information regarding the stroke survivors which participants provided during the interviews was used to determine the MRS score (Appendix 16) by the researcher as described earlier in section 5.6.5.

Additionally, in action research projects, as many participants as possible must be involved in the process of data analysis so that it becomes a collaborative process of negotiation (Waterman et al., 2001; Winter and Munn-Giddings, 2001). These authors further add that it is important that the interpretations or findings are fed back to other participants for their contribution and amendment. This was the case in this study as findings from the interviews were shared electronically with all members of the VAG for their comments and reflection. Furthermore, the findings were presented to the

wider stroke and research audience via a peer-reviewed poster presentation at the 11th National UK Stroke Forum in Liverpool, 2016 and the Edge Hill University Postgraduate Research Symposium in 2016 and 2017. This aimed at aiding the learning process of the research student through the articulation of findings.

5.7 Exploratory phase: part two

During the second part of the exploratory phase, a modified Delphi survey (Keeney, Hasson and McKenna, 2011) (two rounds) was utilised to gain consensus from the family caregivers of stroke survivors and staff working within stroke services on the most important items to be included in the CAT-S. This was followed by a consultation with an expert panel. This phase was conducted between February - July 2017.

5.7.1 Delphi technique

The Delphi technique is a structured process that uses a series of questionnaires or rounds to gather information and is continued until group consensus is reached (Murphy, 1998; Hasson, Keeney and McKenna, 2000; Keeney, 2015). Other methods of gaining group consensus such as the nominal group technique (NGT) exist and were considered during the conduct of this study. However, with NGT, the group is normally small consisting of up to ten people (Cantrill, Sibbald and Buetow, 1996), whilst other authors such as Black (2006) recommend eight to twelve members. This was contrary to the aim of the study, which sought to gain consensus from a larger number of people. Black (2006) recommends that to gain greater ownership of the decision that emerges, it may be politically necessary to include a larger number of those who form the target audience for the output.

In this part of the exploratory phase, views were sought from a wider population who would potentially use the CAT-S in clinical practice such as family caregivers who support stroke survivors and staff working within stroke services. Additionally, the Delphi has an advantage of overcoming geographical boundaries as face-to-face meetings are not a requirement as opposed to the NGT which requires at least one meeting from the participants (Black, 2006; Hutching et al., 2006). The limitations of the NGT subsequently made the Delphi survey the more preferred method to use.

In a classical or traditional Delphi technique, the first round adopts an inductive approach, which begins with a qualitative round in the form of an open-ended question (Hasson, Keeney and McKenna, 2000; Keeney, Hasson and McKenna, 2011). This approach has been criticised as it can result in lengthy second-round questionnaires, making it difficult to sustain the experts' interest in the study (Proctor and Hunt, 1994; Green et al., 1999; Keeney, 2015). In addition, other authors argue that the inductive approach may not produce the level of information that a thorough literature review would (Miller, 2001).

Another approach highlighted in the literature is referred to as a 'modified' Delphi approach where instead of the traditional open-ended first round, the panel of experts are presented with pre-selected issues upon which to form a judgement in the first round (McKenna, 1994). Pertinent pre-selected issues can be developed from a review of the literature, interviews, focus groups or consultation with key stakeholders (McKenna, 1994; Keeney, Hasson and McKenna, 2006). Similarly, this approach has also been criticised as it could limit the available responses. However, the advantage

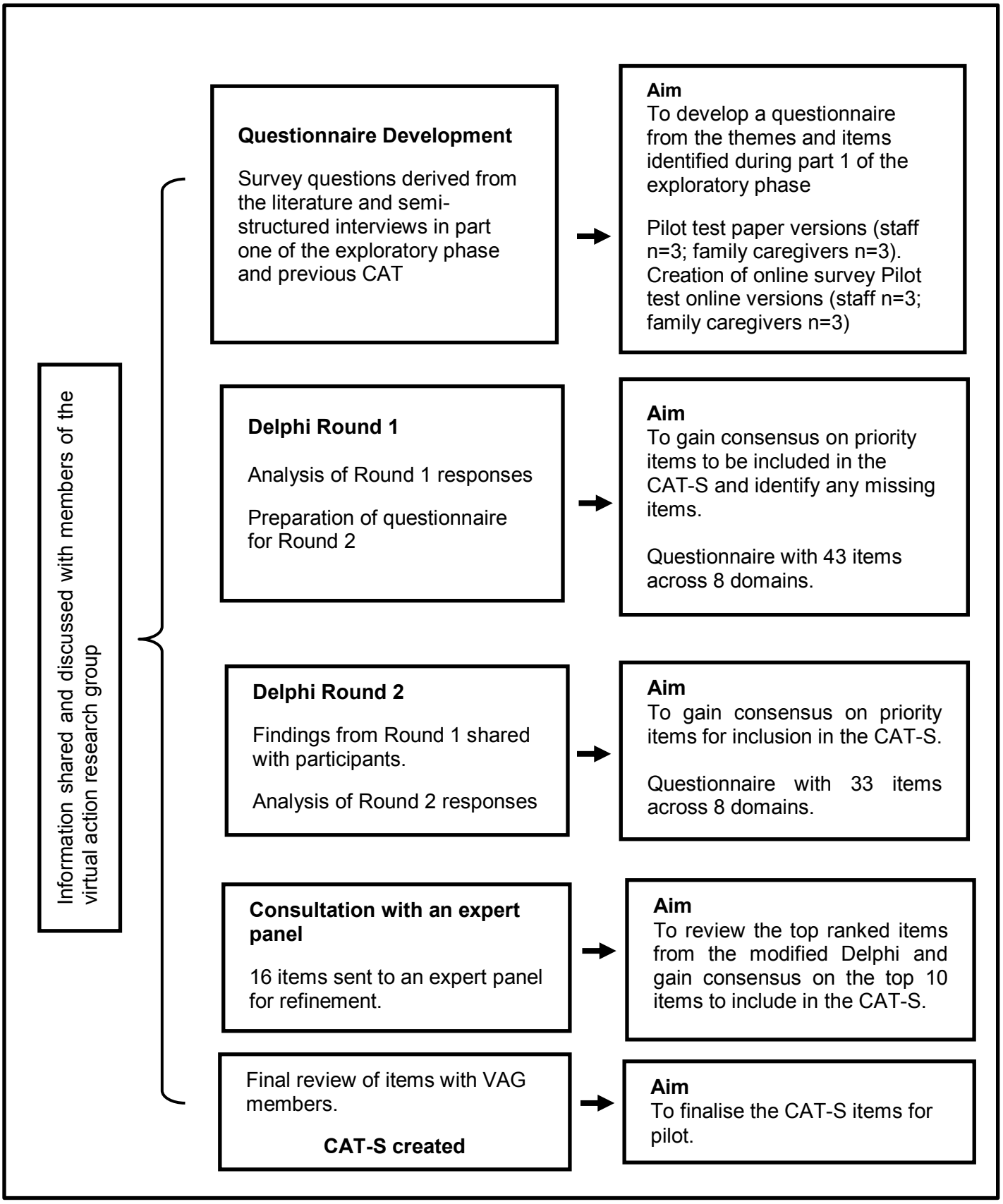
of modifying the open- ended first round with pre-selected issues or items is that the Delphi technique becomes more efficient as a method that has the potential to be very time- consuming (Jenkins and Smith, 1994; Keeney, 2015).

In this study, the choice of the modified Delphi approach was driven by the underpinning methodology and needs of the study (Keeney, Hasson and McKenna, 2006). As stated previously in Chapter 4, a thorough review of the literature had already been completed as part of the exploratory phase. Furthermore, in accordance with the study aim and objectives, semi-structured interviews were conducted as part of the exploratory phase to establish the experiences of stroke family caregivers locally. Based on these activities, it was deemed appropriate to adopt a modified Delphi approach for this study. The modified Delphi approach has been previously utilised in other stroke studies in the UK (Fisher et al., 2011; Philp et al., 2013) and Australia (McGrath et al., 2019) as well as the development of the original CAT (Knighting et al., 2015).

Nonetheless some limitations of the Delphi technique have been reported. These include a poor response rate (McKenna, 1994; Keeney, Hasson and McKenna, 2006), whilst other authors have criticised the scientific respectability of the method particularly with issues concerning consensus, the number of rounds required and the definition of experts (Sackman, 1975; Green et al., 1999; Hasson, Keeney and McKenna, 2000). However, the use of electronic questionnaires adopted in this study enabled people from a wider geographical area of the UK to participate (see Chapter 7, Tables 21 and 22), thereby strengthening the findings. The insights provided by this

wider group were important in this study as the CAT-S is intended for use with multiple health and social care professionals and voluntary sector staff working within stroke services across the UK. To ensure transparency and rigour, each round of the modified Delphi survey had an explicit focus (Jünger et al., 2017). Ethical approval was obtained prior to the commencement of data collection for the modified Delphi survey. Figure 7 provides an overview of the modified Delphi process that was conducted in this study and the aim of each phase of the Delphi process.

Figure 7: The modified Delphi process



5.7.2 Questionnaire development

The construction of the initial self-completion questionnaire was based on various elements. The literature regarding questionnaire development was reviewed and considered an appropriate tool because it enables data to be collected from a large number of people (Oppenheim, 1992; Denscombe, 2014). The overall aim of this study was to adapt the CAT and develop the CAT-S specifically for use with family caregivers supporting stroke survivors. The eight topics utilised in the development of the original CAT (Knighting et al., 2015) were therefore reviewed as a starting point to map findings from the literature and the interviews in part one of the exploratory phase. The eight topics included: caring situation, caring role, relationship with health and social care professionals, respite and emergency care, financial support and assessments, carers health and well-being, support for the carer and end of life and planning (Table 14).

A meeting was then held with members of the supervisory team who have extensive experience in family caregivers' research and were part of the team that developed the original CAT. The items under each topic were discussed. The forty-four items that were utilised in the development of the CAT were also reviewed and compared with the items for the CAT-S. Further discussions were held on items that were present in the CAT development but did not match the interview findings from part one of the exploratory phase of this study such as the topic concerning end of life and planning. Decisions were made on whether to retain or remove the item based on the literature concerning the needs of family caregivers of stroke survivors and key stroke policy documents, such as the National Stroke Strategy (DH, 2007), National Institute for Health and Care Excellence (NICE) guidelines for stroke care (NICE, 2008) and the

Intercollegiate Stroke Working Party (ISWP) stroke guidelines (ISWP, 2012, 2016). This resulted in forty-three items under eight topics that were included in the questionnaire (Appendix 19). Table 14 provides a summary of the number of items under each topic.

Table 14: Number of items under each topic

Topic	Number of items
Topic 1 Caring situation	**7**
Topic 2 Caring role	**8**
Topic 3 Relationship with health and social care professionals	**3**
Topic 4 Respite and emergency care	**3**
Topic 5 Financial support and assessments	**7**
Topic 6 Carer's health and well-being	**7**
Topic 7 Support for the carer	**5**
Topic 8 End of life and planning	**3**
Total number of items	**43**

In keeping with the participatory nature of action research, the list of forty-three items under the eight topics was shared electronically amongst the members of the VAG. Comments were received which enabled reflection amongst group members. No items were added or removed from the list, however, this resulted in a few changes to the wording on some of the items. To ensure a lack of ambiguity in the wording of the items and the layout, the questionnaire evolved through three versions before it was ready to be piloted.

Two questionnaires were finally developed, one for family caregivers and the other for

staff working within stroke services. Both questionnaires comprised three sections, with Sections A and B having exactly the same questions for both cohorts (family caregivers and staff). Section A comprised the 43 items under eight topics as described above. Participants were asked to rate the importance of each of the 43 items for inclusion in the CAT-S using a five-point Likert scale from 1 ‘not at all important’ to 5 ‘extremely important. A Likert scale is a psychometric scale commonly used in all types of survey research and disciplines (Jones and Rattray, 2015; Polit and Beck, 2017). Since the Delphi technique is concerned with agreement and consensus, the five-point Likert scale is commonly used in Delphi surveys (Keeney, Hasson and McKenna, 2011). Additionally, under each topic, the participants were asked to select the most important item that they think should be included in the CAT-S. A comment box was provided at the end of each topic and the respondents were invited to write their comments on that topic such as any missing items or other relevant general comments under that topic (Winter and Munn-Giddings, 2001).

The questions in Section B sought to collect views from the participants on the development of the CAT-S and its potential use in practice. Additionally, the respondents were asked to rank the eight topics in order of priority from one ‘most important topic’ to eighth ‘least important topic’ (Knighting et al., 2015). In Section C, the participants were asked to provide anonymous demographic information. There was a slight difference in Section C between the family caregiver and the staff questionnaires. Stroke family caregivers were asked to provide information relating to their caregiving role whereas staff provided information relating to their professional experience. The family caregiver questionnaire had an additional section on the last

page that contained useful national contacts of organisations that support the family caregivers of stroke survivors to enable them to seek support where necessary (Webster, Lewis and Brown, 2014). Both questionnaires were made available in two formats (paper and electronic). An example of the questionnaire is provided in Appendix 20.

5.7.3 Questionnaire pilot

A pilot was conducted for each of the questionnaires (family caregivers and staff). A total of six family caregivers and six staff took part in the pilot of both the internet - based questionnaire and paper versions of the survey (three in each group). Piloting is a key stage in the development of a questionnaire as it allows the pre-testing of a measure ahead of the main study (Jones and Rattray, 2015; Polit and Beck, 2017). Each questionnaire was tested for the quality of information gathered, the data collection process and the time taken to complete it.

An internet-based questionnaire was created using the Survey Monkey® software and paper formats of the questionnaire were also made available. An email containing a link to the staff online questionnaire was sent to a convenience sample of former colleagues working on a stroke unit in London (n=3), a nurse, an occupational therapist and a physiotherapist. To pilot the family caregiver survey, an email containing a link to the survey was sent to the colleagues of the research student (n=3), two of whom were previous family caregivers of stroke survivors and one was a caregiver to a non-stroke patient. Furthermore, the paper version of the questionnaire was distributed to family caregivers (n=3) in London. The paper version of the staff survey was

distributed to colleagues (n=3) working within the Faculty of Health and Social Care at Edge Hill University. Reviewers were invited to comment on the clarity of the questions, the survey layout and time taken to complete the survey. All family caregivers and colleagues completed and returned the questionnaires within ten days of receiving them. The questionnaires took a minimum of 15 minutes and a maximum of 25 minutes to complete. A few minor changes were made to the layout of both questionnaires following the feedback received. Furthermore, in Section C, Question 2 on both questionnaires, another option was added to the gender question “prefer not to say”. The feedback received from the respondents was positive and they all felt that the questionnaires were suitable to be used as a data collection tool.

5.7.4 Delphi participants

Studies that employ the Delphi technique use individuals who have knowledge of the topic being investigated, which McKenna (1994: 1221) defines as a ‘panel of informed individuals’. The participants in this phase of the study were the family caregivers of stroke survivors and staff working within various stroke services in the UK. Purposive sampling which focuses on the conscious selection of certain subjects believed to be knowledgeable about the issues under study was adopted (Hunt and Lathlean, 2015; Polit and Beck, 2017). Additionally, a snowball sampling technique was utilised (Burns, Grove and Gray, 2011; Procter, Allan and Lacey, 2015). This is where participants were asked to pass on the email containing the study link to their colleagues to widen participation to the study. The inclusion criteria for family caregivers was the same as part one of the exploratory phase of this study as described in Section 5.5.2 of this chapter. The inclusion criteria only applied to staff who have direct contact with stroke

survivors and their family caregivers as part of their role. Furthermore, staff needed to have been in their role for six months or longer. The rationale for this was to seek views from staff with experience of working with stroke survivors and their family caregivers who can draw upon their practical experience. Excluded were staff who have been in their role for less than six months and staff who do not have direct contact with stroke survivors and their family caregivers, such as administrative staff and voluntary sector staff in managerial positions.

5.7.5 Recruitment

Stroke family caregivers

Flyers advertising the study (Appendix 21) were initially distributed to three sites of a national stroke charity that participated in the first part of the exploratory phase in the North West of England. However, due to challenges with recruitment as a result of another study collecting data from stroke family caregivers in the same region, recruitment was extended to four other sites of the same national charity in London, Kent, Surrey and Blackburn. The number of participants in Delphi survey panels vary considerably depending on the purpose of the study (Hsu and Sanford, 2007). Sample sizes of between 4 to 3000 have been reported in the literature (Cantrill et al., 1996; Keeney, Hasson and McKenna, 2011). A total of 400 paper questionnaires were distributed (Round 1; n=150, Round 2; n=250). The community-based stroke coordinators at these centres assisted in providing study information sheets to family caregivers during carer support group meetings as well as during home visits. The individuals willing to participate were asked to complete the paper questionnaire and return it directly to the research team in a sealed, self-addressed envelope that was

provided.

Additionally, the study was advertised on the website of a national stroke charity under the 'Talk Stroke' section and on their Twitter account to allow stroke family caregivers to participate on a national level. A link directed those who wished to participate to the survey page which was created online using Survey Monkey®. A covering text and an information sheet with the contact details of the research team as well as an independent point of contact accompanied the survey. Participants were asked to confirm that they have read the participant information sheet by ticking a box on the front page of the survey. Implied consent was assumed upon completion of the survey (Blair, Czar and Blair, 2014; Jones and Rattray, 2015). Since the survey was available in two formats, participants were reminded that they should only complete the survey once using their preferred method. Due to the nature of the recruitment strategy, it is not possible to establish what the population size was from which the sample was recruited. This is recognised as a potential limitation as stated in Chapter 10 (10.2.2).

Staff

The modified Delphi survey was distributed electronically to a potential total sample of 1653 staff working within various stroke services in the UK (Table 15). The potential sample was calculated based on the total number of members provided by the recruiting organisations. However, the nature of recruitment makes it impossible to establish the exact number of staff who were approached due to some staff being on annual leave or absent due to sickness. This has been recognised as a potential limitation of the current study. An email containing the survey link was emailed to approximately 53 staff of a national charity (North-West) through the Regional Director

who acted as the gatekeeper. The Regional Director then forwarded the email containing the survey link to other Regional Managers of the national stroke charity to pass on the email containing the survey link to their staff through the snowballing sampling technique (Procter, Allan and Lacey, 2010; Polit and Beck, 2017). To recruit health and social care professionals working within stroke services across the UK, emails containing the link to the survey were sent out to approximately 200 members of the UK Stroke Nurses Forum, 200 members of the Scottish Stroke Nurses Forum (SSNF), 650 members of the Association of Chartered Physiotherapists in Neurology (ACPIN), 350 members of the Royal College of Occupational Therapists and 200 members of the Scottish Stroke Allied Health Professionals Forum (SSAHPF) inviting them to participate in the Delphi survey. In both surveys, i.e. staff and family caregivers, a covering text and information sheets with contact details of the research team accompanied the survey. A screening question was presented at the beginning of each survey to establish the participants' eligibility. Implied consent was assumed upon survey completion (Blair, Czaja and Blair, 2014; Jones and Rattray, 2015).

Table 15: Summary of the number of emails sent by recruiting organisations

Recruiting organisation	Number of emails sent by gatekeepers
Association of Chartered Physiotherapists in Neurology (ACPIN)	650
National Stroke Nursing Forum (NSNF)	200
Royal College of Occupational Therapists (COT)	350
Scottish Stroke Allied Health Professionals Forum (SSAHPF)	200
Scottish Stroke Nurses Forum (SSNF)	200
National stroke charity	53
Total number of emails sent	1653

In addition, flyers advertising the study were distributed to the same three sites described in the previous section. The administrators at each of the sites assisted in providing study information packs containing the study information sheet as well as the questionnaire to staff. Individuals willing to participate were asked to complete the questionnaire and return it directly to the research team in a sealed pre-paid, self-addressed envelope that was provided.

5.7.6 Delphi rounds

The Delphi technique is essentially a multi-stage approach with each stage building on the results of the previous stage to achieve consensus (McKenna, 1994). The provision for feedback and opportunity to revise responses requires that the Delphi has at least two rounds (Keeney, 2015). However, there are currently no strict guidelines in the literature on the number of rounds a particular study should have. This depends on the available resources and whether the Delphi sequence was initiated with one broad question or with a list of questions or events and considerations of sample fatigue (Hasson, Keeney and McKenna, 2000; Keeney, Hasson and McKenna, 2011).

In this study, the modified Delphi survey consisted of two rounds. In both rounds, participants were asked to provide their comments on items under the eight topics described earlier in this chapter (section 5.7.2, Table 14). See Appendix 19 for the 43 items contained on the questionnaire and Appendix 20 for an example of the questionnaire that was used. This involved rating the items on a Likert scale from 1 (not at all important) to 5 (extremely important) (Knighting et al., 2015; 2016). A

comment box was provided at the end of each topic for participants to provide comments or add any items that they felt were missing under that topic. In the second part of the survey, participants were asked their views of personnel to complete the CAT-S with stroke family caregivers and how often the needs should be reviewed. The third section of the survey collected anonymous demographic information about participants, geographical location, professional role for staff and how long they had been providing care for family caregivers (See Appendix 20).

The results from Round 1 were summarised and shared in Round 2 in the same way as the first round (Keeney, Hasson and McKenna, 2006). Additionally, a request was made to the gatekeepers for reminder emails to be sent out to all staff a week after the survey commenced and three weeks afterwards to optimise the response rates for the web-based surveys (Denscombe, 2014; Tod, 2015). However, due to the organisational approach to recruitment and the reliance on gatekeepers, it is difficult to establish whether the reminder emails were sent out or not. This is recognised as a potential limitation as discussed in Chapter 10 (10.2.2). Each round of the survey was planned to be open for a period of four weeks but in both rounds the family caregiver survey was extended to eight weeks due to poor response rates. To address the low response rate from family caregivers, following Round 1 of the survey, the research student attended further carer support meetings and spoke to gatekeepers at other sites of the national stroke charity in other regions of the UK to raise awareness of the study. Staff in both rounds only completed the electronic questionnaire, however, stroke family caregivers completed either the paper or electronic questionnaire in both rounds.

5.7.7 Data analysis

The survey provided both qualitative and quantitative data. Details of the procedures that were taken to analyse both data will be presented below.

Analysis of quantitative data

Quantitative data from both surveys were exported from Survey Monkey® and entered into IBM SPSS Statistics for Windows (Version 23. Armonk, NY: IBM Corp.) for analysis. Data from the paper questionnaire (family caregivers) was first entered manually into Survey Monkey before being exported into SPSS together with the data that was collected from the electronic questionnaire. The analysis was done separately for the family caregiver and staff cohorts and then for the combined sample (total sample). None of the questionnaires had incomplete ratings. However, some questionnaires with complete ratings contained incomplete demographic data and were included in the data analysis (Bannon, 2015). A total of 53 questionnaires (family caregivers n=3, staff n=50) had no responses and were excluded from the analysis.

Various ways of analysing the quantitative output from consensus development methods exist, however, they all share the same goals which include: determination of the group's view (some measure of central tendency) and the extent of agreement within the group (a measure of dispersal) (Hasson, Keeney and McKenna, 2000; Black, 2006). Black (2006) further added that since group views are rarely normally distributed, the median rather than the mean should be used to report measures of central tendency. Murray and Jarman (1987), however, argue that although the median and mode are typically used, the use of the mean is also permissible in some cases. Nonetheless, most authors advocate the use of the median compared to the

mean for the purposes of providing statistical feedback to the panel of experts between rounds (Hasson, Keeney and McKenna, 2000; Black, 2006; Keeney, Hasson and McKenna, 2011). However, the mean is calculated in the final round, where the overall final analysis takes place, and the mean is utilised to rank the items in order, from most important to least important (Keeney, Hasson and McKenna, 2011). Descriptive statistics were therefore used in this study to explore the measures of central tendency (median) and dispersion (interquartile range (IQR)) to identify the ratings of both staff and caregiver cohorts and the total sample for individual items and for the ranking of items (Hasson, Keeney, McKenna, 2000).

Level of consensus

As stated earlier in this chapter, the aim of the Delphi technique is to reach consensus, however, in the literature, there are no agreed upon levels of consensus in Delphi studies and no sets of guidelines exist (Keeney, Hasson and McKenna, 2000; 2011). To ensure rigour and transparency, it is important that each study has a pre-determined criterion for consensus (Keeney, Hasson and McKenna, 2006; Von der Gracht, 2012; Jünger et al., 2017). The two most commonly used criteria for consensus are statistical response and percentage levels (Keeney, Hasson and McKenna, 2011). Consensus depends upon the aims of the research, sample numbers and resources, however, a decision must be made in consultation with the literature (Keeney, Hasson and McKenna, 2011).

Some authors suggest that if stricter criteria are used, then it is usually difficult to obtain consensus (Fink et al., 1984; Keeney, Hasson and McKenna, 2011) and, thus, recommend agreement from at least two-thirds of participants (Fink et al., 1984). In

the current study, the consensus was set at the outset at 70% and the participants (in each cohort or in the total sample) had to rate the item equal to, or greater than a median of 4 (very important). The selection of 70% was not based on any theoretical or methodological criteria, instead it was established following a review of the literature and identifying studies which had similar topics and aims. Furthermore, 70% has been previously suggested as a strong cut-off point (Sumison, 1998; McKenna, Hasson and Smith, 2002). The 70% consensus level was also utilised in the development of the original CAT (Knighting et al., 2015, 2016).

The level of consensus within each cohort and the total sample were assessed by reviewing the frequencies for each item to see the percentage of the total sample who rated the item at the level of 4 or above. Table 16 presents the pre-determined consensus criteria that were utilised in this study. Descriptive statistics were used to describe the sample for each round according to demographic data and clinical experience for staff and the caregiving role for the stroke family caregivers (Hauck, Kelly and Fenwick, 2007).

Table 16: Summary of the pre-determined criteria used in this study to accept or reject an item

Criterion for accepting an item	At least 70% of the caregiver and professional cohort rated an item as (4) 'important' or (5) 'extremely important'.
Criterion for re-rating an item	If 70% of one cohort or the total sample rated an item as (4) 'important' or (5) 'extremely important' but the other panel did not, suggesting disagreement between the panels.
Criterion for rejecting an item	Any items that did not meet the 70% criterion in either the panel or the total sample.

In a classical or traditional Delphi approach, statements that have reached consensus

tend to be set aside at this stage, only retaining those where consensus has not been reached for further consideration in subsequent rounds (Keeney, Hasson and McKenna, 2011). However, a possible disadvantage of this approach is that the questionnaire does not become shorter and thus there is an increased risk of losing expert panel members. In other studies, a modification to this approach has been adopted where items with clear disagreement according to the pre-set criteria are removed as authors sought to refine and reduce the priority items (Keeney, Hasson, McKenna, 2006; Von der Gracht, 2012; Knighting et al., 2016). Therefore, in this study, a further modification was adopted to refine and reduce the number of items to be included in the CAT-S. This involved eliminating the items that did not meet the pre-determined 70% criterion. The reduction of the items was important in the development of the CAT-S to ensure a short screening tool.

In Round 2, respondents were provided with group consensus ratings for each of the items from Round 1. Similarly, as in Round 1, respondents were asked to rate each item under the eight topics on a five-point Likert scale for a second time. The same quantitative data analysis and criteria as applied in Round 1 was applied in Round 2. In addition, as previously described in Section 5.6.7, the overall analysis was conducted at this stage as this was considered the final round of the modified Delphi survey (Keeney, Hasson and McKenna, 2011). Therefore, the mean for each item was calculated in each cohort (family caregivers and staff) and the total sample to allow more specificity for ranking purposes of the priority items to include in the CAT-S (McDonough et al., 2011). Open text comments (qualitative data) from family caregivers and staff in both rounds were subject to thematic analysis (Braun and

Clarke, 2006) as described in Section 5.6.6 of this chapter.

5.7.8 Consultation with an expert panel

In order to further refine the items for inclusion in the CAT-S, consultation with an expert panel was undertaken. This consultation was in accordance with the underpinning philosophy of action research, as described in Chapter 4. Furthermore, a consultation was considered appropriate in this study to ensure that the final product (CAT-S) was fit for purpose (Hermans and Cutting, 2013; Knighting et al., 2015). The expert panel consisted of nine members of the existing VAG (three family caregivers, five staff working for a national stroke charity and a specialist stroke medical doctor).

The community stroke physiotherapist who was originally part of the VAG changed employment and was no longer in contact with the group. In addition, three family caregivers who had participated in the previous phases of the study and volunteered to be involved in additional data collection were contacted and invited to be part of the expert panel to finalise items to be included in the CAT-S. The decision to add stroke family caregivers to the expert panel was made in conjunction with the supervisory team to increase family caregivers' representation and contribution due to their low participation in both rounds of the modified Delphi survey. The plan was to match the number of stroke family caregivers and staff, thus allowing family caregivers' views to be heard. The final membership of the expert panel consisted of six stroke family caregivers and six members of staff working within stroke services in the UK.

<u>Data collection and analysis</u>

The panel was invited to review the 16 highest ranked items across the eight topics

identified in Round 2 of the modified Delphi survey and provide any comments and highlight any missing items. Furthermore, they were also asked to select their top 10 items from the list. A participant information sheet was circulated to all members of the expert panel together with a short questionnaire that was developed. Data collected from the short questionnaire were subject to the same analytic processes as in Round 2, i.e. to identify the consensus within both staff and stroke family caregiver cohorts and the total sample as described earlier in section 5.7.7. This analysis resulted in identifying the top 10 ranked items for inclusion in the CAT-S. Open text feedback from panel members was subjected to thematic analysis (Braun and Clarke, 2006), as described in Section 5.5.6 of this chapter.

5.8 Implementation phase

During the implementation phase, a pilot of the CAT-S was undertaken in the North West of England between October – November 2017. The pilot aimed to test the feasibility of recruitment, methods of data collection, the usability and usefulness of the CAT-S in practice to identify stroke family caregivers needs for those supporting stroke survivors. Piloting is recognised as being important to ensure a tool is fit for purpose and identify potential issues including the acceptability of CAT-S to family caregivers and community- based stroke coordinators (Burns, Grove and Gray, 2011; Polit and Beck, 2017). The opinions of the community-based stroke coordinators were sought on the usability of the CAT-S.

5.8.1 CAT-S pilot

The CAT-S for pilot consisted of the 12 items that were prioritised from the modified

Delphi survey. The items were categorised under two main topics: the caregiving situation and caregivers' health and well-being. Questions under the two topics were regarding information about stroke, the behaviour of the stroke survivor, whether the family caregiver needed support to manage their own emotions, respite support and their relationship with healthcare professionals. These items are reported later in Chapter 7. The CAT-S also comprised of a method of scoring the responses from stroke family caregivers. This was done to identify the number of alerts on the CAT-S, decide on the frequency of review required and any individual action plans. Similar to the original CAT (Knighting et al., 2015), the statements on the CAT-S could either be scored green (low risk alerts) amber (medium risk alerts) and red (high risk alerts). The scoring of the alerts on the CAT-S was subjective to the family caregivers in agreement with the community-based stroke coordinators. Red and amber alerts were prioritised for action. The back of the pilot CAT- S form contained guidance for staff on the next appropriate action to be taken based on the number of identified alerts. This guidance, however, did not replace the staff members' professional responsibility for taking appropriate action. Participants were also asked to provide demographic details such as age, gender, relationship with the stroke survivors and whether they had completed a carers assessment. The CAT-S used in the pilot was anonymised following an agreement with the recruiting organisation.

5.8.2 Developing the CAT-S for piloting

Prior to conducting the pilot study, an initial draft version of the CAT-S was created using the 12 items prioritised in part two of the exploratory phase. The CAT-S was developed based on the design and principles of the original CAT (Knighting et al.,

2015, 2016). Seven sections were created as presented in Figure 8.

Figure 8: Sections of the CAT-S

Section 1: Demographic information
Section 2: The top 12 items to identify and screen stroke family caregivers for potential needs prioritised in Chapter 7 (Table 34)
Section 3: An alert thermometer to record the number of medium or high alerts
Section 4: Suggested general guidance on action to take when an alert is identified
Section 5: Section to document actions taken or to be taken
Section 6: Space to record the date of the next review
Section 7: Space to document the time taken to complete the CAT-S

The first section of the draft CAT-S included space to document brief demographic information of the family caregiver such as gender, age, the length of time they have been providing care and the relationship to the stroke survivor. However, as previously discussed in Chapter 5 (methods), the CAT-S for piloting was anonymous and therefore did not include the family caregiver's name or residential address. The second section contained the top 12 items prioritised by the expert panel (Chapter 7, Table 34). The items were categorised under the two main topics: current caring situation and the carer's health and well-being depending on the focus of the item. The two topics (current caring situation and carer's health and well-being) were highly ranked in the modified Delphi as presented in Chapter 7. Section three had the alert thermometer from the original CAT to record the number of high or medium alerts (Knighting et al., 2015, 2016). In section four, the suggested next steps section was included, providing guidance to staff for addressing each item scoring a medium or high alert in section two. Section five had space to document up to four priority alerts

requiring action. Also included under this section were boxes for staff to record any immediate action taken, next steps, name of the person responsible for the following up action, and a date for when the action would be followed up. Section six contained space for when and who would conduct the review. The final section had space for staff to record the amount of time taken to complete the CAT-S (Appendix 22).

5.8.3 Consultation with VAG members

The initial draft version of the CAT-S was shared electronically with members of the VAG. They were enthusiastic particularly with the colour, design and the picture of the thermometer. Members, however, suggested modifications to some sections of the CAT-S. In section one, the VAG members suggested an additional space to include the item regarding the carer's assessment, i.e. *'if the carer has had a carer's assessment'.* Staff felt that the information concerning the carer's assessment was required at the beginning of the conversation with the family caregivers as this would provide an opportunity for them to establish any support services accessed by the family caregiver. Additionally, this could possibly save time and avoid duplication of referrals to some services. The item regarding the carer's assessment was therefore included under section one as a yes or no question. In the second section, the item that had been ranked 4th by the expert panel *'would you like help to cope with any aspects of your caring role?)'* was considered to be too direct for some family caregivers who may be reluctant to state whether they are able to cope or not. It was suggested that this question be changed to '*do you currently have any needs or concerns about looking after your [x] or your own health and well-being'?* VAG members felt this change would be more welcoming to family caregiving and still elicit

similar information regarding coping. Furthermore, the question would serve as an opening question for family caregivers to identify other areas of need not specified on the CAT-S.

Additionally, it was suggested that two of the 12 items '*Do you feel that professionals involve you in decision making by seeking your knowledge and expertise about the care needed by the person they care for?'* and '*Do you feel that you receive the support you need from professionals at the time you need it?'* should be combined. VAG members felt the two questions would elicit similar discussions when completing the CAT-S. The two items were therefore combined and rephrased to *'Do you feel involved in decision making and listened to by professionals about the care needed by [x]?* No further changes were proposed to the remaining sections (three to seven) of the CAT-S. The CAT-S that was developed and piloted in this study is presented in Appendix 22.

5.8.4 Participants

There is limited guidance with respect to sample size for pilot studies, however, Hertzog (2008) suggests that for assessing the clarity of instructions or items wording, acceptability of formatting, or ease of administration, a sample of 10 or even fewer may suffice. Drawing upon the initial pilot of the CAT (Knighting et al., 2015), the CAT-S was to be piloted with a potential sample of ten participants (family caregivers n=6; community-based stroke coordinators n=4) based at one of the sites of a national charity. According to Streiner and Kottner (2014), newly developed tools should not be validated using the data set in which the tool was developed as this may lead to

very optimistic results. Careful considerations were undertaken to recruit participants from a site that did not participate in previous phases of the study. Furthermore, the community-based stroke coordinators confirmed with potential participants that they had not previously participated in the study. The inclusion criteria for stroke family caregivers in this phase were the same as for the exploratory phase (see Section 5.6.2).

5.8.5 Recruitment

A meeting chaired by the research student was held with the manager and community-based stroke coordinators at one of the sites of a national charity that took part in the exploratory phase of this study inviting them to participate in the pilot study. They were briefed about the study, shown the CAT-S and further discussions were held on how to complete the CAT-S. The community- based stroke coordinators were also given the staff guidance sheet (Appendix 23), which contained procedures to be followed during the pilot and instructions on how to complete the CAT-S and a staff feedback form (Appendix 24). During the meeting, the next steps section of the CAT-S for pilot was finalised. Furthermore, the stroke coordinators were given consent forms for the stroke family caregivers. A training session was conducted to discuss with the stroke coordinators how to obtain informed consent from the family caregivers. Involving the coordinators in the consenting of the stroke family caregivers to the study, complements action research where participants are involved in research (Waterman et al., 2001; Winter and Munn-Giddings, 2001). A list of the local support services available to stroke family caregivers was compiled with the guidance of the community-based stroke coordinators. They were informed that the completion and

return of the CAT-S and the staff feedback form indicated their consent to participate. Below is the procedure on the processes that were followed to recruit stroke family caregivers and administer the pilot CAT-S.

Step one – A week prior to conducting their scheduled home visit, the community-based stroke coordinator posted the participant information sheet (PIS) to family caregivers who support stroke survivors. When conducting the home visit, the community-based stroke coordinator confirmed if they received the PIS and whether they have considered taking part in the pilot study. If the stroke family caregiver did not receive the PIS in advance, the community stroke coordinator was not able to conduct the CAT-S with the stroke family caregiver.

Step two – If the stroke family caregiver received the PIS and agreed to take part, the community-based stroke coordinator asked the stroke family caregiver to complete a consent form agreeing to take part in the study by conducting the pilot CAT-S with the community-based stroke coordinator. Participants completed the CAT-S jointly with the community stroke coordinators. Family caregivers were asked to respond to questions on the CAT-S regarding their caring situation and their health and well-being. The scoring system described earlier in section 5.8.1 was used to score the items as low, medium or high-risk alerts. Additionally, community-based stroke coordinators were asked to complete an action plan for any medium or high-risk alerts identified on the CAT-S together with the stroke family caregivers (Appendix 22). Consent was sought from the stroke family caregivers to pass their details to the research student to contact them regarding a face- to-face interview approximately

four weeks afterwards.

Step three – The community-based stroke coordinator then completed a staff feedback form and upon returning to their office, they securely stored the staff feedback form, the consent form completed by the stroke family caregiver and the pilot CAT-S in a locked cupboard in the Manager's office. These were then collected by the research student afterwards.

Step four – Approximately four weeks after the CAT-S administration, the research student contacted the stroke family caregiver to arrange a face-to- face interview.

5.8.6 Staff feedback form

As stated previously above, a short feedback form was developed and attached to the pilot CAT-S for staff to complete after using the CAT-S with stroke family caregivers. Staff were asked to complete nine closed questions and three open ended questions Participants were invited to provide feedback on whether the instructions on the CAT-S were easy to follow, if the questions read well, and whether they felt any questions were missing on the CAT-S. Furthermore, they were asked to state if the questions led to appropriate discussions with the caregivers. Open ended questions on the feedback form requested staff to provide information regarding storage of the CAT-S, staff groups to complete the CAT-S with family caregivers and the ideal time to complete the CAT-S. See Appendix 24 for the staff feedback form.

5.8.7 Data analysis

Data collected from the CAT-S was analysed using frequency distributions to present

information concerning the number of alerts identified, the time taken to complete the CAT-S and the next steps taken (Polit and Beck, 2017). Findings from the CAT-S pilot are presented in Chapter 8.

The nine closed questions on the staff feedback form were subjected to quantitative analysis. The feedback form contained binary questions which were coded as 1 for a 'yes' response and 2 for a 'no' response (Flick, 2011; Polit and Beck, 2017). Data were then analysed using frequency distributions to present information regarding staff feedback. As stated above in section 5.8.6 above, the questions on the feedback form were mainly regarding the usability of the CAT-S. During data analysis, no missing data to the closed questions were identified on the forms. The open-comment sections of the staff feedback form were subjected to content analysis according to Elo and Kyngas (2008), as previously described in the previous section. Details of the questions on the feedback form are presented in Appendix 24.

5.9 Evaluation phase

The evaluation phase aimed to explore the experiences of using the CAT-S from the perspectives of family caregivers and the community-based stroke coordinators. This phase was conducted between October - December 2017. Short semi-structured interviews were arranged with the six stroke family caregivers who completed the CAT-S during the implementation phase to gather their personal views when using the CAT-S. One participant requested a telephone interview, despite having previously agreed to have face-to-face interviews. Authorisation to conduct a telephone interview for this participant was obtained from the acting Chair of the University's FREC in

December 2017. As previously stated in Chapter 4 (Section 4.9.4) the overlapping nature of the action research phases (Meyer,1993) meant that the staff feedback forms that were completed by the community-based stroke coordinators during the CAT-S pilot (intervention phase) formed part of the evaluation phase.

5.9.1 Participants

The sample strategy for this small pilot was to include all the six family caregivers who took part in the pilot and consented to be interviewed as described earlier in section 5.8.4. Participants were contacted four weeks after the pilot in order to capture their experiences of using the CAT-S with the community-based stroke coordinators. The four-week gap was to allow any assessments, action plans and support that could result from the CAT-S. However, it was discovered that one participant who completed the CAT-S with the community-based stroke coordinators during the pilot was supporting a stroke survivor residing in a residential home. This participant did not meet the inclusion criteria as described in Section 5.6.2 of this chapter and was therefore excluded from the interviews resulting in five participants who took part in the semi-interviews.

5.9.2 Semi-structured interviews

Four face to face semi-structured interviews and one telephone interview were, therefore, conducted to gather the personal accounts of stroke family caregivers' experiences of using the CAT-S. The rationale for choosing interviews and the processes followed were similar to those described in the exploratory phase (Section 5.6.1). Similarly, an interview guide (Polit and Beck, 2017) was also developed and

piloted. The questions on the interview guide included the amount of time taken to complete the CAT-S with the community-based stroke coordinators and whether the family caregivers received any support after completing the CAT-S. Furthermore, they were invited to comment on the staff's approach in relation to the participants needs. Family caregivers were also asked to provide their views regarding regular assessments and their preferred staff to complete the CAT-S. See Appendix 25 for the interview guide. All interviews were audio-recorded digitally. The interviews were held at the stroke family caregivers' home and lasted approximately 10 minutes. The same processes followed during part one of the exploratory phase as described in Section 5.6.5 were followed to conduct the interviews. Each participant was interviewed once.

5.9.3 Data analysis

In the evaluation phase, a content analysis approach was utilised to analyse the data that was collected from the stroke family caregivers who took part in the CAT-S pilot. According to Cole (1988), content analysis has been described as a method of analysing written, verbal or visual communication, the essence being to extract the appropriate data from the message to answer the research question. Some authors suggest that when conducting exploratory work in an area where not much is known, content analysis may be suitable for the simple reporting of common issues mentioned in data (Green and Thorogood, 2018). Since the interviews that were conducted as part of the evaluation of the CAT-S were very brief, content analysis was viewed as the ideal method of data analysis. Furthermore, in content analysis it is possible to analyse data qualitatively and at the same time quantify the data (Gbrich, 2007). Conversely, other approaches to qualitative data analysis such as thematic analysis

provide purely qualitative, detailed and nuanced account of data (Braun and Clarke, 2006; Clarke and Braun, 2013).

Computer-assisted qualitative data software, NVivo version 12 ® (QSR, International, 2018) was used to assist with organising and storing data for easy retrieval and management (Polit and Beck, 2017). The three-phase process of content analysis according to Elo and Kyngas (2008) (preparation, organisation and reporting) was followed. Firstly, data were transcribed verbatim into written form and checked for accuracy by listening to the audiotapes. The transcripts were then read and re-read and this provided an opportunity to be immersed in the data and obtain a sense of the whole interview (Elo and Kyngas, 2008; Vaismoradi, Turunen and Bondas, 2013). The whole interview was considered to be the unit of analysis in this study (Graneheim and Lundman, 2004). In content analysis, the researcher can choose between manifest content of data (developing categories) and latent content (developing themes) before proceeding to the next stage of the data analysis (Elo and Kyngas, 2008; Vaismoradi, Turunen and Bondas, 2013). Although both latent and manifest deal with interpretation, some authors suggest that the depth of interpretation and level of abstraction varies, with manifest content being concerned with surface meaning (Graneheim and Lundman, 2004). Since the interviews that were conducted in this phase of the study were short with the sole aim of evaluating the CAT-S, a decision was made to focus the analysis on manifest content.

The next stage is the organising stage. This involved open coding and collecting codes under potential categories and comparing the emerged coding's clusters together and

in relation to the entire data set (Elo and Kyngas, 2008; Vaismoradi, Turunen and Bondas, 2013). The interview guide used to conduct the interviews served as a guide regarding the manifest content of the text. This involved extracting the appropriate data to answer the questions on the interview guide (Cole, 1988). The final stage involved reporting the results through the categories and telling a storyline (Vaismoradi, Turunen and Bondas, 2013). To enhance the credibility of the findings, a member of the supervisory team independently read two of the five transcripts to establish if they agreed with the data categories (Silverman, 2017). The identified categories from the interviews in this phase are presented in Chapter 8.

Staff feedback forms

As previously explained in Chapter 4, in reality, the phases of action research overlap (Meyer, 1993). In this study the staff feedback forms that were collected during the implementation phase as part of the CAT-S pilot were analysed as part of the evaluation phase to understand the perspectives of the community-based coordinators when completing the CAT-S. The processes described earlier in this chapter (5.8.7) were followed to analyse data from the feedback forms.

5.10 Enhancing quality and rigour

As discussed earlier in this chapter, different strategies were utilised to collect (qualitative and quantitative) data including semi-structured interviews, modified Delphi survey, the CAT-S and staff feedback forms. This section provides a discussion of how rigour of the data collection and analysis methods was assured during the conduct of this study, to allow the quality of the methods to be evaluated.

In all the phases of the current study purposive sampling (Hunt and Lathlean, 2015) was adopted to ensure that the data collected was rich and relevant to the research aim and objectives. Furthermore, each data collection tool was subjected to piloting with family caregivers and staff as described in earlier sections of this chapter prior to being used. This was done to evaluate the effectiveness of the methods and modifications were made following the pilot as required (Polit and Beck, 2018). Additionally, feedback on all the data collection instruments was sought from members of the VAG (as described in section 5.5) which comprised of family caregivers of stroke survivors and staff working within various stroke services in the UK. This enabled face or content validity of the data collection instruments to be established (Jones and Rattray, 2015; Lacey, 2015). Existing literature suggests that active involvement of service uses in research can have positive impact on outcomes, by ensuring its appropriateness and relevance (Brett et al., 2014; Dovey-Pearce et al., 2019).

As stated previously (sections 5.6.6 and 5.9.3) thematic analysis (Braun and Clarke, 2006) and content analysis (Elo and Kyngas, 2008) were used to analyse qualitative data from the exploratory phase and evaluation phase respectively. Nonetheless, data analysis was conducted concurrently with data collection in both phases and this allowed validation of statements in subsequent interviews (Lathlean, 2015). Moreover, verbatim quotations from different participants are presented in the findings Chapters (6, 7, 8) to illustrate and support the findings. This will allow readers to assess the consistency between data presented and the accuracy of interpretations made. This further adds to the transparency and trustworthiness of the findings and interpretations

of the data (Tong, Sainsbury and Craig, 2007).

The use of inter-rater techniques where more than one researcher codes the transcripts is recommended when analysing qualitative data (Saks and Allsop, 2007; Polit and Beck, 2018). Comparing coding can increase consistency, reliability and validity in both coding and subsequent analysis. Half of the transcripts in each phase of this study were independently analysed by two members of the supervisory team. The final themes were also discussed with the supervisory team to establish agreement with the findings (Bryman, 2016). In addition, peer debriefing (Polit and Beck, 2018) which involves external validation with peers of researchers to review aspects of the inquiry was achieved through monthly supervisory team meetings and feedback received from VAG members.

A modified Delphi survey was utilised to gain consensus on the most important items to include in the CAT-S. As such, the recommendations of conducting and reporting Delphi studies (CREDES) (Jünger et al., 2017) were consulted during the second part of the exploratory phase. This included the justification for the choice of the Delphi technique, planning and design, study conduct and reporting as described earlier in this chapter (section 5.7). The importance of having an agreed, pre-determined criteria for consensus in Delphi studies is reported to be vital for helping to establish rigour and transparency (Keeney, Hasson and McKenna, 2006; 2011). It has been argued that researchers do not always give sufficient attention to group stability or pre-determining the criteria for consensus when they adapt the method and analysis to achieve their study aims (von der Gracht, 2012). Chapters 5 and 7 of this thesis have included comprehensive details about the criteria for consensus to accept, reject or

re-rate an item in the Delphi survey. Moreover, the criteria is also prominently displayed in Table 16 earlier in this chapter and Tables 28,31, 32 in Chapter 7 and full Round 1 and Round 2 analysis (Appendix 26 and 27). Providing a clear guide for what the criteria was and the rationale for how it was selected, enhanced the transparency of the process (Diamond et al., 2014). Furthermore, the wide geographical spread of participants in the Delphi survey as illustrated in Chapter 7, enhances generalisability of the findings (Bryman, 2016). Using an additional expert panel after the survey to comment on the CAT-S items may have reduced the potential for researcher bias by providing a level of external validation to the findings (Jünger et al., 2017). This also ensured face and content validity of the CAT-S (Streiner, Norman and Cairney, 2015).

The credibility of a study rests on the procedures implemented and the self-awareness of the researcher throughout the research process (Mantzoukas, 2005; Denscombe, 2014). As described earlier in section 5.3 of this chapter, a personal diary was maintained where all the events that occurred, including data collection and the decisions made were recorded. Recording the thoughts and decisions made, enhanced dependability and transparency of the process.

Since qualitative data was collected during the exploratory and evaluation phases, the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong, Sainsbury and Craig, 2007) was also followed. Full extracts of the CREDES recommendations and the COREQ checklist and how they were applied to the current study are provided in Appendix 28 and 29.

5.11 Overview of the CAT-S study

As described in the earlier sections of this chapter, this study consisted of various phases where different data collection methods were utilised. Table 17 provides a summary of the whole study including the data collection methods that were utilised in each phase.

Table 17: Overview of the CAT-S study

Study phase	Aim	Data collection method and data type	Participants
Pre-exploratory phase April- May 2015	To establish the value of the study	Phone calls, emails, face-to-face meetings (Qualitative data)	18 current stroke family caregivers 11 members of staff Staff and family caregivers were from two stroke charities (a local stroke charity in London and a national charity in the North-West of England) and a stroke unit in London. **Total n = 29**
Exploratory phase (part one) February -May 2016	To identify factors contributing to burden during caregiving post stroke To seek the views of stroke family caregivers about the CAT	Literature review and semi-structured interviews (Qualitative data) Semi-structured interviews	16 stroke family caregivers from a national stroke charity in North West England. **Total n = 16** As above
Exploratory phase (part two) Modified Delphi Round 1 and 2 Consultation with an expert panel February -July 2017	To gain consensus on the most important factors from part one of the exploratory phase for inclusion in the CAT-S To seek expert panel review of the top 10 items to include in the CAT-S	A two-round modified Delphi survey (Quantitative and qualitative data) <u>Round 1</u> 43 items across 8 topic domains <u>Round 2</u> 33 items across 8 topic domains Consultation and consensus selection (Quantitative and qualitative data)	249 questionnaires were completed across two rounds from staff and stroke family caregivers nationally <u>Round 1</u> staff n = 101 stroke family caregivers n = 12 <u>Round 2</u> Staff n = 117 stroke family caregivers n = 19 8 members of the VAG and 3 stroke family caregivers who participated in part one of the exploratory. (n = 11; staff n = 5; stroke family caregivers n = 6) **Total n = 260**
Implementation and Evaluation phase October-December 2017	To pilot the readability and usability of the initial CAT-S	Pilot study of the CAT-S (Quantitative and qualitative data)	Community-based stroke coordinators n = 4; based at a national stroke charity in the North West of England. Stroke family caregivers n = 5 **Total n = 9**
Total number of participants in the study = 314			

5.12 Chapter summary

This chapter started with an overview of the study aim, phases of the study and objectives for each phase. The ethical considerations that were adopted throughout the conduct of this study were then presented. The data collection techniques and processes that were followed to collect data in each phase were then discussed together with the data analysis processes that were conducted. The next chapter will present the findings from each phase of the study starting with the first part of the exploratory phase.

Chapter 6: Methods and findings (Exploratory phase - part one)

6.1 Introduction

In this chapter, the findings from the semi-structured, digital audio recorded interviews that were conducted in part one of the exploratory phase will be presented. As described in the previous chapter (Section 5.5), the interviews aimed to achieve two objectives, therefore, the findings are reported in two sections. In the first part, the two main themes identified as factors contributing to burden when providing care to individuals following a stroke, namely the effects of caregiving and unmet needs, are presented. The themes provided a basis for generating items that were included in the questionnaire used in the modified Delphi survey. In the second section, findings regarding stroke family caregivers' views about the CAT are reported. Before presenting the results, a brief description of the sample is presented to provide contextual information and aid with the understanding of the findings.

6.2 Sample and data collection

As discussed in Chapter 5, participants were recruited through support groups run by a national charity organisation that supports stroke survivors and their families. Additionally, community-based stroke coordinators assisted with recruitment during their routine follow-up visits to the stroke survivors' homes. Twenty-one potential participants were identified, however, five did not meet the inclusion criteria. Two were not residing at the same address with the individual who suffered the stroke, one was a paid caregiver and the other potential participant was recently bereaved. The final

sample consisted of 16 family caregivers who were supporting stroke survivors living at home. The interviews were carried out between February 2016 and May 2016, lasting 35- 55 minutes. The participants selected the venue for the interviews. Eight were conducted at the participants' home, five at the venue where stroke family caregivers meet for their support group, two in a café and one in a University office.

6.3 Characteristics of participants

All 16 participants described themselves as White British and were residing at the same address with the stroke survivor. As indicated in Table 18, the majority were female, i.e. 11 out of 16. The youngest participant was aged between 35 and 44 years, three were aged 76 years or above, whereas half of the participants (n=8) were aged between 66 and 75 years. Fourteen of the participants were the spouses, i.e. husband or wife of the individual who they were supporting. Two participants referred to themselves as partners to the stroke survivor but since they were co-habiting partners, they will be referred to as spouses throughout this chapter. Ten had retired from their employment, two were still employed and providing care at the same time, whereas four reported having given up work due to their caregiving responsibilities. The duration of caregiving ranged from four months to eleven and a quarter years. The majority of the participants had been providing care for less than a year. Only four family caregivers confirmed they had completed a carer's assessment. Another four were unsure if they had or not, whereas two were awaiting assessment. The remaining six family caregivers denied having been offered or completed a carer's assessment.

Characteristics of the stroke patients

As previously described in Chapter 5 participants were asked to provide some information about the individual who they were supporting using the modified rankin scale (MRS) (Van Swieten et al., 1988) to establish the level of disability of the stroke survivor. The level of disability of the stroke survivors ranged from slight disability to moderately severe disability (MRS 2-4). See Table 19 for a summary of the MRS scores. Furthermore, four were family caregivers for individuals who had suffered a recurrent stroke (second stroke). Semi-structured, face-to-face interviews were carried out between February 2016 and May 2016, lasting between 35 and 55 minutes.

Table 18: Characteristics of each participant

Participant	Sex	Age in years	Relationship to stroke survivor	Employment	Stroke survivor MRS*	Duration of caregiving in years and months	Carer's assessment
P1	M	66-75	Husband	Retired	3	2 years, 2 months	No
P2	F	36-45	Partner	Unemployed	4	7 months	Awaiting
P3	M	66-75	Husband	Retired	4	4 months	Yes
P4	M	76 plus	Partner	Unemployed	2	9 months	Yes
P5	M	56-65	Husband	Employed	2	1 year, 10 months	No
P6	F	66-75	Wife	Retired	3	1 year	No
P7	F	76 plus	Wife	Retired	3	9 months	Uncertain
P8	F	76 plus	Wife	Retired	2	10 years	Uncertain
P9	F	66-75	Wife	Retired	4	4 months	Awaiting
P10	F	56-65	Wife	Unemployed	3	1 year, 6 months	Uncertain
P11	F	66-75	Wife	Retired	3	10 months	No
P12	F	66-75	Wife	Retired	4	6 years	Yes
P13	M	56-65	Husband	Unemployed	4	11 years, 3 months	Yes
P14	F	66-75	Wife	Retired	3	11 months	Uncertain
P15	F	66-75	Wife	Retired	4	9 years	No
P16	F	56-65	Wife	Employed	2	4 years	No

**Modified Rankin Scale (range 0-6) a higher reading indicates greater disability*

Table 19: Summary of participants' demographic characteristics

Characteristics	Number n=16
Age	
36-45	1
46-55	0
56-65	4
66-75	8
76+	3
Sex	
Male	5
Female	11
Employment	
Employed	2
Unemployed	4
Retired	10
Duration of caregiving in years	
Less than 1 year	7
1-2 years	4
3-5 years	1
6 years or more	4
Stroke survivor MRS	
MRS 2	4
MRS 3	6
MRS 4	6

6.4 Data analysis

As previously described in Chapter 5, a thematic analysis approach as advocated by Braun and Clarke (2006) was adopted to analyse the data. Six sub-themes were identified as factors contributing to burden when providing care to individuals following a stroke: physical effects, emotional effects, socio- economic effects, respite, lack of information and signposting and additional support. Similarities were sought amongst the sub-themes and they were finally clustered into two main themes called 'effects of caregiving' and 'unmet needs' (Table 20).

Table 20: Main theme and sub-theme formation

Main Theme	Sub-theme	Ideas in relation to the research question
Effects of caring Definition: Include statements that refer to any negative effects of caring on the caregiver	Physical effects	Tiredness Physical strain (hard work) Increasing workload Increasing age Pre-existing medical conditions
	Emotional effects	Carers emotions Patients emotions and behaviour
	Socio-economic effects	Changes to lifestyle Relationships with friends Money issues Employment Benefits
Unmet needs Definition: Include responses that relate to any unmet needs to support with caring as described by the caregivers	'A ship without rudder' (Lack of information and signposting)	Information on discharge Information on available support services Information about stroke Uncertainty of the future
	'Time off caring' (Respite)	Time off caring Barriers to accessing respite care
	Additional support	Paid caregivers Listening ear Equipment Parking

In the next section, the results will be presented under the two main themes. In order to substantiate the findings, verbatim quotations will be used to illustrate the subthemes and demographics to preserve the context of the individual record. In the presented extracts, […] indicates that some text has been removed. Superfluous text was removed to assist the contextual flow of the data. To comply with ethical research practices and maintain confidentiality, the unique numbers that were given to participants during the interviews will be used instead of their real names. Participants will, therefore, be labelled as follows: participant number-relationship to the stroke survivor (e.g. wife, husband, and partner) and age range (P1-Wife-56-66). For the two

participants who identified themselves as a partner of the stroke survivor, their gender will also be included, i.e. (P2-Partner-Female-36-45).

6.5 Effects of caregiving

Family caregivers highlighted various negative effects that they had encountered since taking on the caregiving role. These can be classified into physical (relating to the caregivers' physical well-being), emotional (relating to the caregivers' psychological wellbeing) and socio-economic (relating to their finances and life-style). These effects will be discussed separately below.

6.5.1 Physical effects

Most family caregivers stated that they were providing some physical care to support their spouses. This involved assisting them with activities of daily living such as washing and dressing, mobility and toileting. Others also reported assisting their spouses with therapy as part of rehabilitation. One participant described how she was assisting her spouse with 'physio' and the instructions that she received from the physiotherapists:

> '*I have to do some physio with him, like we have the FES which is like an electrolysis machine that we've been putting on his leg to try and get his muscles in the right way, because they've turned round in his leg, and it seems to be doing good things, so we've been carrying on with that, and I've been told to lie him on his face down twice a day for half an hour by the physio, so I also have to do that in-between his dinner time…' P2-Partner-Female-36-45.*

It was evident from the accounts of most caregivers that supporting stroke survivors can be physically demanding and some participants referred to their caregiver role as

'hard work'. For the majority, this was mainly the case during the initial days following hospital discharge, as over time, the stroke survivors' functional abilities seemed to improve. Furthermore, the caregivers appeared to develop some coping strategies as they became accustomed to their role. One caregiver shared her experiences during the early days following her husband's stroke. She explained the initial assistance that she provided to support her husband with his mobility and that following improvement, he no longer required that support:

> '*He couldn't walk unaided, couldn't stand up unaided […] literally couldn't do anything…. and I was there 24/7 for him, I still am, but I'm backing off a lot more now […] to stand up originally I'd have to sort of put my hand underneath his bottom and lift him up… it was hard work, but now he's actually walking round the bungalow with the aid of a stick which is unbelievable, absolutely unbelievable...' P10-Wife-56-65.*

On the contrary, for other participants, this was not the case as the stroke survivors' abilities either remained the same or had worsened, particularly for those individuals who suffered a recurrent stroke. One participant mentioned that her husband's mobility had deteriorated following a second stroke. She reported that she was currently receiving additional support from paid caregivers to assist her with meeting her husband's personal hygiene needs. However, in the absence of the paid caregivers, she had to support her husband with toileting:

> '*Since the December one I mean things just went bad to worse. I can't get him up; I've got two carers four times a day… but yeah, it's just hard… because in between, I've got to transfer him onto what's called a perching stool because it's the right height for him to sit on and use that…' P9-Wife-66-75.*

Increasing workload was also highlighted by participants and this appeared to result

in tiredness. In addition to supporting their spouses with activities of daily living and rehabilitation, caregivers had to undertake additional duties such as accompanying the stroke survivor to hospital appointments and the stroke club (these are meetings mainly organised by charity organisations to provide long- term peer support to stroke survivors and their families). Furthermore, they had to perform regular household chores such as shopping, laundry and minding pets. For most caregivers, the increasing workload led to tiredness:

> *'I've got to get all the jobs done and everything done but I also got to look after [Person Name]… you realise just how much it takes out of you and that's when the real problems start to… not problems but difficulties start to hit. I can still cope with it physically, but I feel shattered a lot of the time…' P3-Husband-66-75.*

Disturbed sleep at night was another challenge that was mentioned, and this appeared to be a contributing factor to the tiredness. Caregivers cited various reasons for their disrupted sleep such as waking up to assist their spouse with toileting and positioning. In some instances, spouses reported sleeping in separate rooms due to limited space, especially when the stroke survivor required special equipment such as a hospital bed and a commode to be cared for at home. In such instances, participants stated that they experienced difficulties sleeping as they constantly wanted to check on their spouse as explained by one caregiver:

> '*Well I go to bed then I'll go out a couple of hours and then once I wake up, I'm listening… peep over the bannister… see if the lights have gone on… but you're always conscious because he's in the back room… we've got like a hospital bed and I go upstairs, but no I'm conscious, I don't sleep very well' P9-Wife-66-75.*

For other family caregivers, their increasing age appeared to intensify the physical demands of providing care. The participants stated how they were increasingly struggling to adequately support their spouse due to their own poor health and frailty. Some also reported pain as a result of pre-existing medical conditions. This seemed to have a negative impact on their ability to perform activities such as lifting. Commenting on her age and a pre-existing medical condition one participant stated:

> *'I think because I'm 74 at the moment it's a bit old to be heaving people around yeah […] and you know like I've got polymyalgia, can't even say it now, you know which could affect me eventually I don't know, but I find it hard sometimes I ache and sometimes am alright' P12-Wife-66- 75.*

The above views were also highlighted by another caregiver who seemed to be struggling with her own poor health but was also the main caregiver for her husband. She articulated her plans to seek support in the near future to relieve the strain as follows:

> *'Because I am 70 next birthday, and I have told him that I can't be doing this on my own, he's going to have to within the next couple of years, he's going to have to have carers in to get… because I do have a really bad foot and I'm finding it difficult to walk, I do have high blood pressure and I think to myself well in another year or two I will get the carers in just morning and night to take the strain off me…' P15-Wife-66-75.*

6.5.2 Emotional effects

The participants described the emotional effects in relation to the challenges that they were encountering with managing the emotions and behaviours of the stroke survivors as well as their own emotions. These will be presented separately.

Stroke survivors' emotions and behaviours

Most family caregivers indicated that they were providing emotional support to their

spouses as part of their role. Essentially, this involved offering encouragement and reassurance to the stroke survivors 'to raise their spirits' as they adjusted to the devastating effects of the stroke. The majority remarked that this was particularly challenging as there was very little they could do in order to change the situation. Additionally, this support seemed to be continuous due to the fluctuating nature of their spouse's emotions.

It was also apparent from their reports that most caregivers appeared to have adapted to the physical aspects of caregiving, however, managing the stroke survivor's emotions and behaviour remained a major challenge for most, for the longer term. One participant who had been supporting her husband for six years disclosed how over time, she had become 'comfortable' in supporting her husband with his activities of daily living. She also described the living adjustments they had made. However, she reported to be struggling with managing her husband's emotions:

> *'The daily aspects of looking after [Husband Name]… now I mean we've got quite comfortable now in the way we are, because we're doing downstairs living, but I think it's keeping his morale up, but you know I'd say that is the hardest…' P12-Wife-66-75.*

Participants cited a range of behaviours and emotions exhibited by the stroke survivor that they found particularly challenging. They stated: mood swings, short temper, impatience, depression, verbal abuse, social withdrawal and demanding behaviour. They discussed that this was particularly difficult because in most cases it was impossible to reason or negotiate with the stroke survivor due to the underlying cognitive impairments caused by stroke. One caregiver explained how she had to

adjust and re-learn how to live with her own husband as a result of mood swings. The cognitive problems that he had developed following stroke meant that he had become forgetful and lacked insight into his problems. Additionally, the unpredictability of when the mood swings would occur made it particularly difficult for her to deal with. She shared the following:

> *'He's not the same, he isn't the man I got married to and we've had to re-learn to live with each other… […] His temper is short; he's very impatient where before he was a very patient man. He's very irritable at times and his mood swings dramatically [...] there is no point arguing with him because he'll have forgotten in a minute… I don't always know when I walk in how he's going to be and from hour to hour sometimes I don't know how he's going to be…' P16-Wife-56-65.*

Other caregivers mentioned that they had to endure verbal abuse from the stroke survivor. Most appeared to understand the cause of such behaviour as they admitted to having been pre-warned by the medical team or therapists. One participant reported that her husband's verbal abuse gets triggered when she encourages him to perform certain tasks in order to promote his independence. She stated that the consultant (medical) had informed her about this abusive behaviour when her husband was admitted to the stroke unit:

> *'If I tell him to do things, I'm bossy and get told to get lost […] I've been told in no uncertain terms that I'm useless… and helpless… and rubbish. I've been called all kinds, so you know I find that hard, find that very hard to take. The consultant said he'll have highs and lows with that when he came out which is happening...' P9-Wife-66-75.*

In contrast to the verbal abuse, other participants mentioned different experiences

such as dealing with withdrawn and docile behaviour. Caregivers stated that such behaviour resulted in the stroke survivor becoming completely dependent on them, which subsequently resulted in additional emotional strain on the caregivers. This view was well articulated by a caregiver who was supporting her husband who became socially withdrawn after he lost his ability to eat and drink following stroke:

> *'He's become very withdrawn; because he can't eat, he can't have a drink… he can't do anything like that. That is the main consequence. He's had a complete character change really. He's so docile, refers to me for everything… It's like looking after a child really. What do you think [Participant Name] ..., and I mean some stroke people can get quite aggressive and that sort of thing, so I'm thankful he's not like that, but I do feel that everything is on my shoulders really…' P7-Wife-76 plus.*

Family caregivers' emotions

There was a clear emphasis from caregivers that managing their own feelings and emotions was another major challenge that they had to overcome. The frustration or 'feeling upset' was highlighted by most participants. They cited various reasons for this frustration including their changed roles and life-style:

> *'Sometimes I get a little bit upset thinking how it used to be and how it is at the minute [….] I get upset, I do get upset. I don't know really why, but it's just you start thinking about things don't you and sometimes I must admit I still get a bit upset… Sometimes on my own I have a good cry…' P14-Wife-66-75.*

Sharing similar views, another caregiver explained how her frustration surfaced when she accompanied her husband to the stroke club. She stated:

> *'I know they're stroke survivors, and I think that the term "survivors" is great, but they were all damaged people and seeing how well he fitted in was upsetting and also I mean I was there, and I helped make the cups of tea and dish out*

things and all that aspect of it but there was a part of me thinking; is this it? Is this my role for the rest of my life and I found it very upsetting…' P11-Wife-66-75.

For other participants, their spouse's functional disabilities, as well as changes to their personality, were the source of this frustration. One participant described a stroke as 'cruel' in comparison to other medical conditions. She explained that the effects of a stroke to individuals, particularly changes to their personality, surpassed the stroke survivor and affected the entire network of family and friends:

'It's a terrible thing a stroke, it's cruel, and I used to say, better if you had a heart attack and that's it that was before, and I still feel like that. It's so cruel, because it takes so much away not just from the stroke patient but from the family, well everybody, friends because it robs you of a personality really can't it…' P12-Wife-66-75.

Caregivers also reported depression. The sudden nature of stroke resulted in most caregivers taking on their role without any preparation. Some had given up employment to care for their spouse. Additionally, others had to relocate to a different type of accommodation in order to enable the stroke survivor to continue living at home. Such massive adjustments, within a short period, resulted in depression for some caregivers. One participant shared her experience after giving up work to support her husband and the medical treatment that she was receiving after seeking help from her GP:

'*I've been on a very mild anti-depressant since he's had the stroke, very, very, mild, but I think that little bit takes the edge off…' P15-Wife- 66-75.*

Feelings of abandonment, being undervalued, taken for granted and not listened to by health and social care professionals were highlighted by the caregivers. They

indicated that much focus and attention tended to be on the stroke survivor with minimal attention given to them despite the huge amounts of support that they provided to the stroke survivor. One caregiver likened his caregiving role to that of a housewife who hardly gets any appreciation:

> *'Speaking from my own personal observation, the carer becomes like the housewife if you want to put it that way, but the trouble is the carer becomes taken for granted… well not so much won't but doesn't get listened to. They'll turn, and they'll go… […] nobody asks how you are, nobody sees how you are…' P5-Husband-56-65.*

Fear was another emotion that was mentioned by the caregivers. The participants commented on the recurrent nature of stroke and this seemed to be a source of fear for most caregivers. Describing her fears of a recurrent stroke, one participant who was providing support to her husband said:

> *'Well, this is my dread to be honest, that he doesn't have another one. I think he has had just slight ones…' P8-Wife-76 plus.*

Overwhelmingly, the majority of caregivers highlighted challenges in dealing with the emotions and behaviours of the stroke survivor as well as their own emotions.

6.5.3 Socio-economic effects

It was obvious from the caregivers' accounts that the caregiving role presented some negative socio-economic effects upon their lives. These effects were expressed as the changes that they experienced in relation to their social life and their finances.

Social life (Different sort of life)

The participants reported the changes to their social life that had occurred since assuming the caregiving role. They described a different lifestyle in relation to holidays, outings and their interaction with friends. Most discussed how they were struggling to maintain social relationships due to the demands of caregiving. One participant described her experience as a 'different sort of life'. She explained how her social life had completely changed following her husband's stroke as she was unable to go on holidays and outings as previously:

> '*Well it were a totally different way of life for us weren't it and yeah because we went out regular and had holidays and that but all that's not there now and stuff […] I mean we had lots of holidays and as I say we were both crown green bowlers and lots of friends. It is a different sort of a life this than we had before definitely…' P14-Wife-66-75.*

For other participants, their social lives had been affected as they could no longer perform the hobbies that they shared with their spouse. The physical disabilities and cognitive impairments caused by stroke meant that some stroke survivors could not participate in activities such as horse riding, walking and bowling. One participant who enjoyed walking with her husband as a hobby before he had a stroke said:

> *'See we were very much physical, our hobby was walking, we used to go up to the lakes, the Yorkshire dales… so we weren't ones for sitting around, that's probably been the hardest thing really; we were very active…' P12-Wife-66-75.*

The caregivers mentioned some barriers that hindered them from going on holidays and outings such as their unwillingness to leave their spouse behind due to feelings of guilt. Others described how a great deal of planning was required prior to going out

due to the complicated needs of the stroke survivor. They stated that careful considerations were required particularly on issues such as toileting and outdoor mobility when going out, as described by one caregiver whose husband had become incontinent of urine following stroke and was using a urinary sheath to manage his incontinence:

> *'So yeah we try and get out but it is hard getting ready to go out because he has to have like a bag on his leg at the minute […] Yeah, well I think it's in a way it is a little bit hard going out anywhere […] I've got to make sure he's got that thing on, I've got to order a taxi, I've got to do this, I've got to do that. Yeah there's a lot to it…' P14-Wife-66-75.*

For other caregivers, their spouse's cognitive impairment and personality change acted as a barrier for going on holiday. This point was expressed by one caregiver whose wife suffered a stroke that mainly affected her cognition with minimal physical effects. He reported that he was hesitant to take his wife on holiday as her disorientation seemed to worsen in unfamiliar environments:

> *'I've not been on holiday this year, because I went on holiday last year not that I need a holiday as such… but the trouble is if she's in an environment she knows, she's not so bad, but if I went into a brand new environment it takes some adjustment… she gets so so confused…' P1- Husband-66-75.*

Isolation was also highlighted by the caregivers. They described how the demands of caregiving prevented them from engaging in social activities. Most appeared to prioritise the needs of their spouse over their own needs. Furthermore, they struggled to maintain social ties and this resulted in isolation. One caregiver mentioned that although she was able to leave her husband alone at home to attend a church service, she was restricted on the length of time she could leave him alone. Consequently, she

found it difficult to interact with her friends after the church service as she had to rush home to attend to the needs of her husband. This resulted in feelings of isolation:

> '*Well I do go to church, and I have friends at church and I'm finding it harder now because I'm looking after [Husband Name]..., but I'm not mixing with people quite as much and I am isolated… I feel isolated…' P8-Wife-76 plus.*

Finances

It was apparent from the participants that assuming the caregiving role, led to negative financial implications for most caregivers. Four caregivers reported that they had given up employment to care for their spouses. In other instances, the stroke survivor had been the main source of income and subsequently following the stroke, they could not work to provide financial support to their families as explained by one caregiver:

> *'Because he had the stroke and he didn't get paid nothing. Part of my problem when he had the stroke was trouble going on in work, and I did leave because of the stroke… […] this put us in a right mess financially, we're sorted now, but I could have done with help then…' P15-Wife-66- 75.*

The participants also stated the financial hardships they were facing. The lack of income and increasing expenditures to meet the needs of the stroke survivor meant that most caregivers were unable to afford some of their necessities. In order to sustain themselves financially, some caregivers were receiving financial assistance in terms of benefits or charity grants. Some participants stated that they found this financial assistance to be very helpful as reported by one caregiver:

> *'I did get a grant… I'm not sure how much it is a week, about £70 I think, which I pay a young lady who I couldn't do without and she comes in 2 hours a week to help me with housework […] well it enables me to have time to look after [Husband's Name] and not to worry about other things…' P7-Wife-76 plus.*

Although some caregivers were very appreciative of the financial support received, others seemed to be dissatisfied with the benefits they were receiving. They indicated that the amount was insufficient to cater for all their pre-existing commitments including the increasing expenses. In addition, others viewed the timing of these benefits to be unsuitable as they had to wait for approximately six months before they could receive any assistance. One caregiver described how he had struggled to meet some previous financial commitments. He indicated that following his wife's stroke, they both became unemployed as he gave up employment to care for his wife. He stated that the amount of benefits that they were both receiving was insufficient to repay the debts that they had:

> *'When I had to give up work, we had two jobs earning £30,000 a year plus between us, you also got debts for that and to get only £8,000 a year benefits you go; help! ...and eventually we went to a debt management company that should have told us we've just found out they charged us £1,300. They should have told us to go bankruptcy for £500 each…' P13-Husband-56-65.*

Another caregiver expressed her dissatisfaction with the timing caregivers could access benefits. She described how their expenses as a family had immediately increased following her husband's stroke. They suddenly had to rely on taxis for transport when going to church or the stroke club as her husband struggled to use public transport due to reduced mobility. She stated that she had to wait for six months before she could receive any financial support in terms of benefits:

> '*You've got to be six months down the line to get it, even attendance allowance you can't get, and it's in the first six months that you need it because your expenses go up with taxis, and your outgoings increase when someone's ill you know, there's nothing in place really to help…' P6-Wife-66-75.*

Participants also mentioned barriers that prevented them from seeking financial support. A lack of information and advice on financial issues seemed to be a major reason for most caregivers. Most indicated that they were ignorant of their entitlements in terms of benefits whereas others were unaware that such support existed. Others added that they felt embarrassed to ask for financial information as reported by one caregiver:

> *'I could have done with information over money, benefits and legal matters… because you do tend to not to tell people because you're so embarrassed…' P4-Partner-Male -66-75.*

6.6 Unmet needs

The second main theme that was identified relates to unmet needs to support the caregivers with their role. This theme has three sub-themes namely: time off caring (respite), ship without rudder (lack of information and signposting) and additional support.

6.6.1 Time off caring (respite care)

Only a few caregivers mentioned having accessed respite care. For most, there was a clear sense that occasionally, they preferred to have some 'time off' caring. This was to allow time for themselves without constantly thinking about the needs of their spouse. The need for respite appeared not to be affected by the duration of caregiving as caregivers who had been supporting their spouses for less than a year as well as those who had been in their role for much longer, both expressed the desire to have a break. One participant who had been supporting her husband for nine months reported the following:

'What would help me was for him to be taken off my hands so that I could have my head to myself and not constantly thinking about his needs... […] the biggest help to me would be just occasionally for him to have respite care, so that I could have a break you know because it's constant...' P7-Wife-76 plus.

Another participant who had been supporting her husband for six years stated that she had continuously cared for her husband for the entire period without a break including when her husband was hospitalised. She said:

'There's times I'll be honest with you… there's times where you think; oh gosh I can't keep going like this, because I haven't had a day off in that six years, only when [Husband Name] ... was in hospital, but then you're running backwards and forwards to hospital…" P12-Wife-66-75.

Family caregivers appeared to express their need for respite care in varied ways. Some preferred to have a few days to allow them to experience a restful night free of disturbances, whilst others wished to have more than a week to enable them to travel for a holiday. Furthermore, some desired a few hours to allow them to go shopping and socialise with friends. Some caregivers described how it was difficult to go shopping and leave their spouse alone due to safety concerns. Those without family close by explained how this was particularly challenging as they constantly relied on friends to 'sit in' with their spouse for them to go out:

'I'm quite alone really, no relatives round here, plenty of friends but you feel you can't keep asking them to sit in… I want to go out next Tuesday, so I'm trying to think ahead of asking someone in advance, so that I can go out for a couple of hours…' P9-Wife-66-75.

The participants spoke of various barriers that prevented them from accessing respite

care such as their emotional attachment, the reluctance of the stroke survivor, dissatisfaction with the services and lack of information on how to access respite care. One caregiver expressed her emotional attachment as a barrier as follows:

> *'It breaks my heart, so I want to, but I can't, because I miss him when I'm away from him, and he misses me, and it just devastates us, sounds ridiculous but honestly…' P2-Partner-36-45.*

In other instances, it was the stroke survivor's reluctance to go for respite care that prevented them from accessing such support. This reluctance seemed to be caused by the negative experiences encountered by some stroke survivors:

> *'He went into a little nursing home just round the corner, and he hated it, absolutely hated it, he doesn't want to go anymore. I think he feels safe here, and he feels safe with me… […] I certainly don't want him to go if he's reluctant, and not happy, so we just plough on…' P7- Wife-76 plus.*

Other caregivers mentioned the lack of information on how to access respite as a barrier as explained by one caregiver:

> *'To tell you the truth I wouldn't even know how to apply for respite care because no one's ever mentioned it to us […] I wouldn't even know how to go round it…' P13-Husband-56-65.*

6.6.2 Ship without a rudder (lack of information and sign-posting)

The lack of information on support services emerged strongly from the family caregivers' accounts. Furthermore, the participants commented on the insufficient information that they received at the time of hospital discharge. Most reported receiving inadequate information particularly regarding medications. One caregiver

described his experiences with his wife's discharge from hospital as 'a ship without a rudder'. He stated that he had received no information regarding his wife's medication from hospital staff and after his wife was discharged home, he struggled to understand the indication of the medications and how to administer them. He shared the following:

> *'The classic example was as I walked in, they were telling [Wife name] about the tablets and she hadn't a clue what they were talking about…[…] I had to pick it all up by reading labels and they just simply when they saw me they said: "Well that's what it is, ask your wife, she knows. Right be good". And that was our discharge. And you're a ship without a rudder there's nothing, and you don't know about the various pieces that you can get, the various supports that there are…' P5- Husband-56-65.*

Additionally, caregivers highlighted the lack of stroke specific information such as the causes of stroke and secondary prevention strategies, e.g. measures to control blood pressure following a stroke. Others reported the lack of knowledge on the type of foods 'not to give' to the stroke survivor. They emphasised the importance of having such knowledge to enable them to effectively support the stroke survivor and most importantly to prevent another stroke. One participant who was working as a health care support worker but also supporting her husband who suffered stroke stated:

> *'I probably could have done with a lot more education about stroke, but you tend not to seek that kind of information until you need it. Well I certainly didn't. I did from a work point of view I had a lot of training and I did know the basics of it but it's a whole different thing when you're living with it…' P16-Wife-56-65.*

Caregivers also stressed the lack of being signposted to support services as a major challenge that they encountered as in most instances they were uncertain of how and where to seek support. They explained that this was important to allow them to seek timely support and thereby avoid unnecessary suffering. One caregiver described his

struggle to find information about the local carer support group and the stroke club:

> *'The biggest thing to me was knowing where to go for help first you know... […] I mean the main thing is contacts and being told where to go and how to proceed […] I think that's the main thing putting people in the right direction from the beginning…' P1-Husband-66-75.*

The majority of caregivers spoke about uncertainty regarding the expected recovery of their spouse. This appeared to have a negative effect on their ability to plan for the future and what to expect. One participant recalled the conversations that she had with the stroke team regarding her husband's expected recovery:

> *'You're constantly saying; well is he going to get better, and they constantly say "it takes time… we can't tell you, every stroke patient is different", and they tell you that, you must have some idea, but two years down the road I can see where they were coming from…' P10- Wife-56-65.*

6.6.3 Additional support

Caregivers discussed the various support that they had received from family members, friends, healthcare professionals and paid caregivers to assist them with their role. In addition, others mentioned the equipment provided to them such as commodes, shower chair, hospital bed and a feeding pump to support them with providing care for their spouse. Although some were satisfied with the equipment and the support received, others clearly expressed their dissatisfaction. It was evident from what they stated that the absence of such support created additional distress that could negatively impact upon their health and wellbeing.

Family support

Although most caregivers remarked the invaluable support that they had received from family members, others had different experiences. Some caregivers reported that their families lived abroad, whereas in some instances, although families lived close by, support was not forthcoming. Furthermore, caregivers were reluctant to request support, particularly from their children as they had other responsibilities such as employment and raising young children. One participant expressed her disappointment at the lack of support from her family and her spouse's family:

> '*His family aren't helpful, and my family are just really busy, and I'm not making excuses I've only got a small family, [Person Name] ... has a large family, if people helped more, if there was more support there, then maybe things would be better. If his family come in and said one day a week, come on we're taking him out, and we're going to do this that will be a big help, but they just don't…' P2-Partner-Female-36-45.*

Paid caregivers

Some caregivers were receiving additional support from paid caregivers to assist them with providing personal care to their spouse. Others mentioned paying caregivers privately to occasionally relieve them from performing physical tasks such as bathing or showering. However, some caregivers expressed their dissatisfaction with the paid caregivers. Participants cited the lack of flexibility, poor time keeping and incompetence as some of the reasons that discouraged them from accessing this type of support. One caregiver shared the reasons why he discontinued a paid caregiver from coming in to support with providing personal care to his wife:

> '*First of all they would come when they wanted to come… […] always late, and I felt really, how can we say, I didn't feel they were that good if I'm really honest about it… […] they didn't seem to know, you know they were calling in… but I*

thought at the end of the day, they're going to do no better than me, I can do it because I know my wife…' P3- Husband-66-75.

Listening ear

Having a listening ear was another unmet need that was remarked on by most caregivers. Due to the sudden nature of stroke and the relative unpredictability in terms of recovery, most participants described the emotional struggles that they encountered. They discussed their desire to have 'someone' to talk to who could listen to them either face-to-face or over the phone particularly during the initial period following stroke. Although a few appeared to be receiving this support from close friends, the majority indicated that they required this support:

'Whether it's a listening ear or counselling service could be offered to carers especially in that initial phase when you're coming to terms with what's happened, that could be useful… just somebody on the other end of the phone to listen to you, that could really help…' P11-Wife-66- 75.

Additionally, the caregivers discussed their reluctance to seek emotional support from professionals such as their GP for fear of being commenced on medication unnecessarily. Most preferred talking to non-professionals such as staff from charity organisations or fellow caregivers for this support:

'*If you'd talked to somebody who'd had that experience you could say to them then, and I start to hate myself, and they say yeah but it's only natural, don't worry about it, it's just a normal human feeling. Talk to a professional then they'll be writing your prescription or sending you to the funny farm to be assessed which is not what you need…' P5- Husband-56-65.*

Parking

Caregivers who owned a car described the lack of support with parking requirements particularly during the initial phase following stroke when their spouse had multiple hospital appointments. Some explained how the thought of accompanying their spouse to hospital appointments created anxieties regarding parking logistics. Hospital transport seemed not to be an option for some due to the restrictions in some hospitals on who is allowed to accompany the patient. One participant described her experiences of leaving her husband, who had reduced mobility as well as cognitive problems, alone at the hospital entrance whilst she went looking for parking at a location further from the main hospital building. She expressed her views of a temporary blue badge for caregivers:

> *'I think maybe there could be some sort of temporary blue badge that is hospital parking particularly… when we had lots of appointments, that was really difficult because we didn't have a blue badge so it was a question of dropping my husband off near the entrance we needed to go to, and saying to him; wait here, while I go and find parking space which would be in a multi-storey on the hospital car park or something and then coming back to him. If there could have been some sort of temporary thing to cover the visits to the hospital at that time that could have been really useful…' P11-Wife-66-75.*

Equipment

Some caregivers reported delays in receiving equipment whereas others reported not receiving the desired equipment due to cost implications particularly with expensive equipment such as an electric wheelchair. One participant explained how she was still waiting for her husband's arm chair to be delivered eight months after his hospital discharge:

'We haven't got a chair for him to sit on and our couch and stuff is too low for him to sit on, it's too low and far back. He is even in more pain if he sits on the couch the next day… […] we're still waiting for a proper chair for [Person's Name] to sit in and he's been home since July… it's no one's fault, it's just the way government cuts and stuff like that that isn't it you know…' P2-Partner-36-45.

6.6.4 Summary of the challenges experienced by stroke family caregivers

From the findings presented in this chapter, it is apparent that caregivers who support stroke survivors encounter numerous challenges during the provision of care. Additionally, it is evident that they have different unmet needs that can potentially have adverse effects on their overall well-being and quality of life if not addressed. Subsequently, this can potentially affect their ability to continue with the caregiving role. The results, therefore, highlight the significance of assessment as key to understanding their needs to allow appropriate and individualised support to be provided. Furthermore, caregivers clearly require adequate information across the caregiving pathway to enable them to seek help whenever they need it. The next section will present findings in relation to the second objective which was to seek the views of the family caregivers on the CAT.

6.7 Consultation with family caregivers about the original CAT

In this section, findings relating to objective two of the study will be presented. This aimed to seek the views of participants about the usefulness of the CAT in identifying and supporting the needs of caregivers. Halfway through the interviews described in the previous chapter, the participants were shown a copy of the original CAT and a

brief explanation relating to its development and current use was provided. Time was allowed for participants to read the statements and the questions on the CAT. Subsequently, all caregivers were asked to provide their views on the use of the CAT. From the data analysis, three themes were identified, namely the functions of the CAT, the appropriateness of the questions and the missing questions. These themes will be presented separately.

6.7.1 Functions of the CAT

Overwhelmingly, all participants reported positive views about the usefulness of the CAT in supporting the needs of caregivers. Their reasons were varied, however, most viewed the CAT as a tool that would aid in identifying their problems. This view was articulated by one participant who commented that the CAT would help to 'pick up' if she had any problems:

> *'It's asking about how you're coping with the situation isn't it? And putting it actually into little compartments and from there in the ideal world it will pick up if you have got a problem…' P10-Wife-56-65.*

For other participants, the CAT was regarded as useful, as the questions would enable them to reflect about their issues and concerns. Most caregivers remarked how they constantly prioritised the needs of their spouses over theirs. The questions on the CAT would therefore act as a prompt for them to think about their needs as explained by one participant:

> *'There's questions that you wouldn't even think of, because you're too busy to even think, and some of them questions when you read them, and you think about them you think yeah that's right, but it's not something you'd think of, so they are helpful in that way you know…' P2-Partner-36-45.*

Highlighting a similar view, one caregiver appeared to express her frustrations as she was able to relate the questions on the CAT to her own problems. She explained that despite having been in contact with healthcare professionals, no one had previously asked her about her concerns:

> *'A couple of the questions there were putting lights on for me, and nobody has ever asked me those things, and sometimes you feel like you've just got to get on with it, but if somebody was to ask me those questions I could well talk about them…' P16-Wife-56-65.*

For other participants, the CAT was seen as useful as it would emphasise the importance of caregivers and additionally validate their role. Furthermore, others felt that it could facilitate the required support to be received by caregivers:

> *'It would validate in a sense that the carer was important as well, and the physical aspect it could lead to practical help, yes I think it would be really useful...' P11-Wife-66-75.*

Offering reassurance was another function of the CAT that was cited by the participants. They explained that completing the CAT and knowing that there was support would help to put their minds at ease particularly if circumstances were to change. This view was expressed by one participant as follows:

> *'I think you'll feel at least that there is somebody there, you know that if all of a sudden thing change, because as it says things can change, health can change, [Husband Name]... health can change, and things like that…, so yeah I think it would be good…' P12-Wife-66-75.*

Although the majority of the participants had positive views about the CAT, others also emphasised that completing the CAT needed to be meaningful in terms of yielding the

required support for caregivers and not just an additional task. This view was articulated by one participant who stated that completing the CAT should not just be about filling a form:

> *'I think it would be good idea as long as it was followed up properly, not just fill a form in, and then it's part of the statistics that carers need help, or whatever, but if it did get followed through…' P10-Wife-56-65.*

6.7.2 Appropriateness of the CAT items

Caregivers also gave their comments on the appropriateness of the questions on the CAT. Although the participants had been briefed that the CAT was developed with caregivers supporting patients with advanced progressive illnesses such as cancer, most stated that the questions on the CAT appeared to still be relevant to their situation as explained by one participant:

> *'Yes, because alright they might be for cancer, but it's still the same process isn't it of looking after somebody regardless of what the medical condition is. Yeah, I think they are relevant, if you're looking after somebody whether it's stroke, or cancer, or anything they are relevant questions…' P12-Wife-66-75.*

For other participants, although the questions on the CAT were not applicable to their personal situations, they still felt that the questions were relevant to other caregivers who support stroke survivors:

> '*I think these questions they don't particularly refer to me some of them, but I can honestly think they are very necessary in certain incidents I would probably think they need more care than I give… You know, and I think yeah I think these are quite relevant…' P3-Husband-66-75.*

Some caregivers specified the questions that appeared to be relevant to their

situations. They mentioned questions relating to support with providing emotional and spiritual support to the individual being cared for as well as balancing their own needs as explained by one participant:

> *'Yeah, the big one is the emotional, yeah; any help to provide emotional, or spiritual care. That can be very demanding, and also help to balance your own needs, because I'm sure others have said it, your own needs just get put sideways…' P16-Wife-56-65.*

The question relating to knowing the named contact was also mentioned by some caregivers. They remarked how knowing who to contact would enable them to seek help when they needed it. One participant summed up what others said:

> *'Those questions are quite good actually especially having a named person to call. I mean if you did need any help for physical things although I don't, it would be handy to know that there is help out there to do it, and that you had someone to come in and do it, so no I think they're quite good actually…' P6-Wife-66-75.*

Other participants also commented on the end-of-life question. They viewed this question to be equally relevant. One participant stated that this was particularly relevant in her situation particularly due to her age:

> *'Well it's relevant for everybody when they're over 80… we know we all haven't got that much time don't we, that's just life…' P7-Wife- 76plus.*

6.7.3 Missing items

Although the participants reported that the items on the CAT were largely relevant, a few commented that stroke-specific questions were missing from the CAT to ensure that it was meaningful to caregivers who support stroke survivors. They suggested adding questions related to the causes and management of stroke as stated by one

caregiver:

> *'So, if your question was; do you need more information about what happens after a stroke, what causes it you know, and how you can deal with that…?' P3-Husband-66-75.*

Additionally, other caregivers proposed adding questions related to secondary prevention of stroke. Most remarked how in some instances they had been uncertain in terms of how to support their spouses particularly with dietary requirements in order to reduce the risk of having another stroke. One participant expressed his suggestion as follows:

> *'So probably about a diet… a question something in there about the diet…' P4-Partner-Male-76plus*.

For other participants, questions relating to the family caregivers' wellbeing appeared to be missing from the CAT particularly those relating to their emotional well-being and socialisation. In relation to this view, one participant provided an example of the type questions to be included in the CAT for caregivers supporting stroke survivors:

> *'Maybe you know; do you feel you need anyone to talk to, or do you feel isolated? Or do you need support emotionally? Do you need some sort of social activities for you yourself…?' P11-Wife-66-75.*

6.8 Chapter summary

In summary, stroke family caregivers highlighted various challenges that they encountered when providing care to individuals following a stroke. Additionally, they expressed positive views about the usefulness of the CAT as a screening tool in identifying and supporting the needs of family caregivers. The participants further

emphasised the need for a similar screening tool for use with stroke family caregivers. A few suggestions were reported regarding some missing items on the original CAT. This was particularly in relation to stroke-specific information and emotional support for the family caregivers. The next chapter will present the findings from part two of the exploratory phase where a modified Delphi approach was utilised to prioritise items for inclusion in the CAT-S.

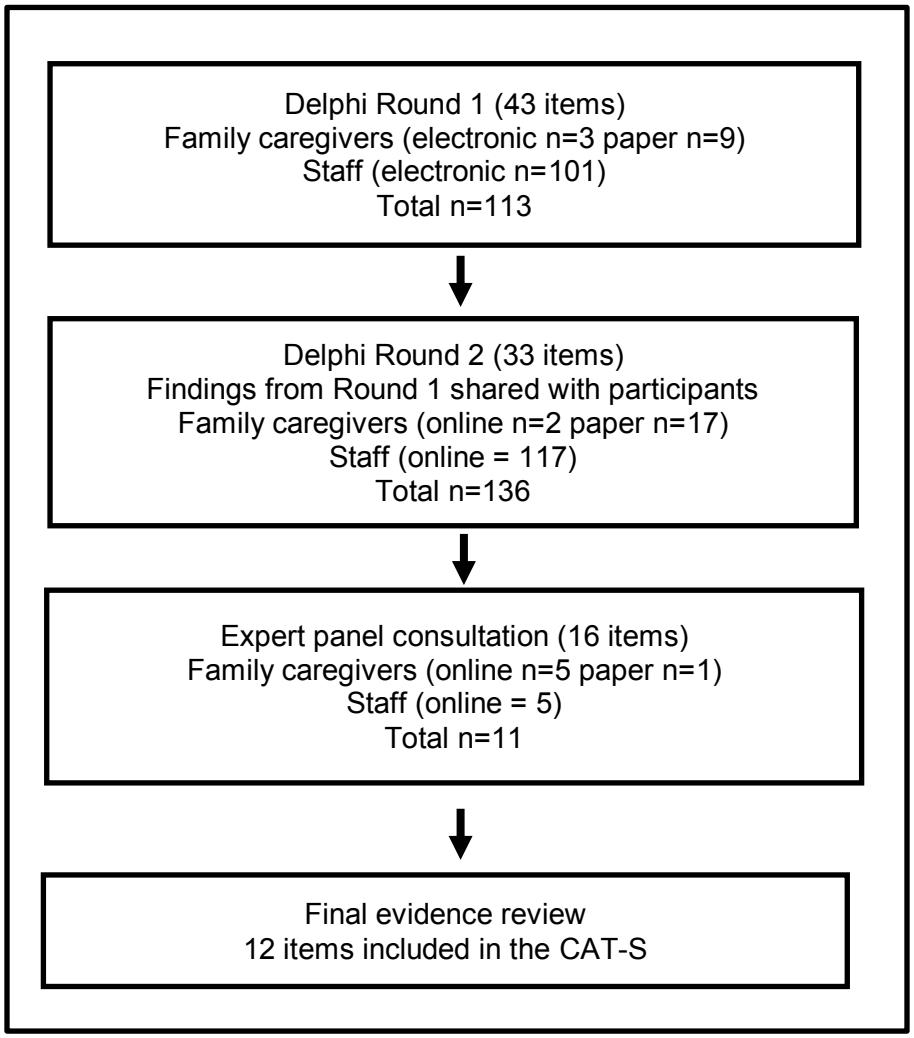
Chapter 7: Methods and findings (Exploratory phase part two)

7.1 Introduction

In this chapter, the findings from a two-round modified Delphi survey that was conducted in the second part of the exploratory phase are presented. The aim of the Delphi survey was to gain consensus from the family caregivers of stroke survivors and members of staff working within various stroke services in the UK on the most important items for inclusion in the CAT-S. Consultation with an expert panel resulted in 12 items that were included in the CAT-S for piloting. Due to the iterative nature of the Delphi technique (the results of one round being dependent on the results of the previous round), the processes and results for each round will be presented separately as is recommended in the literature (Jünger et al., 2017). However, the findings from the open text comment boxes in both rounds of the survey and the first part of Section B (respondents' views on the development and future use of the CAT-S) are presented together at the end of the Round 2 findings. This is to avoid repetition as few and similar comments were identified. Before presenting the findings, a summary of the Delphi rounds and the number of respondents in each round is provided (Figure 9). A brief summary of the methods is provided within this chapter to provide a context for the findings.

7.2 Summary of the modified Delphi survey

Figure 9: Flowchart showing the Delphi rounds and number of respondents in each round



7.3 Delphi Round 1

The questionnaire comprised three sections. See Appendix 20 for an example of the questionnaire. In Section A, the respondents were asked to rate the importance of the 43 items under eight topics for inclusion in the CAT-S. The number of items under each topic ranged from three to eight. As previously discussed in Chapter 5, a five-

point Likert scale was used, from 1 being 'not at all important' to 5 'extremely important' as this is common in questionnaires utilising the Delphi technique (Keeney, Hasson and McKenna, 2011). In accordance with the processes followed during the development of the original CAT (Knighting et al., 2015, 2016), the respondents were also asked to select the most important item under each topic to start the process of gaining consensus. A comment box was provided after each topic. In Section B, the respondents were asked to provide their views on the CAT-S and its future use. At the end of the survey in Section C, they were asked to provide anonymous demographic information. Additionally, family caregivers were invited to provide information regarding their caregiving experience whilst staff provided information about their role.

Round 1 was planned to run for a period of four weeks from February to March 2017. However, recruitment challenges were encountered due to another study collecting data from stroke family caregivers in the same region. Recruitment was therefore extended to three additional sites in London, Kent and Blackburn and, thus, prolonging this round by four weeks. The staff survey was also extended by two weeks following a request from one of the recruiting organisations. This resulted in Round 1 being conducted over a total of eight weeks (February to April 2017). A similar duration of Delphi rounds has been reported in other studies elsewhere (Duffield, 1993; Jünger et al., 2012).

7.3.1 Data analysis

Quantitative data were entered into SPSS Statistics for Windows Version 22.0 (IBM, Armonk, NY: USA) for analysis. As previously discussed in Chapter 5, measures of

central tendency (median) and level of dispersion interquartile range (IQR) were computed to identify the ratings for individual items and determine the spread of responses (Hasson, Keeney and McKenna, 2000; Black, 2006). This was done for each cohort (staff and family caregivers) and then the total sample. The pre-determined criterion for consensus set in this study was 70% of participants in each cohort or in the total sample to rate the item as equal to or greater than a median of 4 (very important) (Hasson, Keeney and McKenna, 2000; McDonough et al., 2011; Knighting et al., 2015). The level of consensus was assessed by reviewing the frequencies for each item to see the percentage of participants who rated the items 4 and above. Descriptive statistics such as frequencies were also used to describe the sample according to demographic data, clinical experience for staff and caregiving situation for the family caregivers (Hauck, Kelly and Fenwick, 2007). A thematic analysis approach (Braun and Clarke, 2006), as described previously described in Chapter 5, was adopted to analyse data from the open text comments from the survey.

7.4 Round 1 findings

7.4.1 Response rate

Family caregivers

It is impossible to state reliably how many family caregivers received the survey in Round 1 due to reliance on gatekeepers (Gelling, 2015; Whittingham, 2016). Additionally, the survey was advertised on the 'talk stroke' section of a national stroke charity website and on social media through their 'Twitter account. Therefore, it is impossible to confirm how many stroke family caregivers saw the advert. The number of paper questionnaires that were sent out has therefore been used to calculate an

approximate response rate (Bowling, 2005; Jones and Rattray, 2015). In this round, a total of 150 questionnaires were distributed across six recruitment sites. Nine family caregivers returned the survey via post and six completed the online questionnaire. However, three of the six online questionnaires had no responses and therefore excluded from the analysis. The response rate was calculated to be 8% based on the 12 complete records that were returned.

Staff

Like the family caregiver cohort, it is unknown how many members of the recruiting organisations received the invitation email and met the inclusion criteria to calculate the staff response rate reliably. The figures obtained from the recruiting organisations were therefore used to calculate a response rate. As described in Chapter 5 a total of approximately 1653 emails were sent out by recruiting organisations as presented earlier in Chapter 5 (Table 15). The online questionnaire was accessed 151 times, however, 50 questionnaires had no responses, so they were excluded from the analysis. The response rate was calculated to be 6.1% based on the 101 complete questionnaires.

7.4.2 Participants

Twelve family caregivers and 101 staff members working in various organisations that support stroke survivors and their families participated in Round 1. The demographic profiles of the two cohorts are presented separately.

Characteristics of family caregivers

As illustrated in Table 21, the majority of the respondents were female (n=9, 75%) two (17%) were male, and one respondent did not disclose their gender. All family caregivers except one described themselves as White – English and the majority were aged over 55 (n=7, 58%). Over half of the family caregivers (n=8, 67%) were from the North-West of England, whilst the rest originated from London, the South-West, the South-East and the East of England. Most respondents (n=9, 75%) were supporting either their spouse or partner. The other family caregivers were providing care to their parent or adult child. All except two family caregivers had been providing care for over a year.

None of the respondents were providing care for less than 10 hours per week, and a third of the family caregivers (n=4, 33%) reported providing care around the clock (24 hours a day). The sample comprised of family caregivers who were mostly retired from employment (n=7, 58%) whereas four (33%) were still employed and providing support to a stroke survivor. The majority were supporting a stroke survivor for the first time (n=11, 92%). Only four respondents (33%) admitted to having completed a Carers Assessment whereas over half (n=7, 58%) denied having completed one. A summary of the characteristics of the stroke family caregivers is provided in Table 21.

Table 21: Characteristics of family caregivers in Round 1

Characteristics	N=12 (%)	Characteristics	N=12 (%)
Gender		***Hours of caregiving per week***	
Male	2 (17%)	11-20	2 (17%)
Female	9 (75%)	21-30	3 (25%)
Prefer not to say	1 (8%)	31-40	2 (17%)
		24 hours a day	4 (33%)
Ethnicity		Other	1 (8%)
White-English	11 (92%)		
Other	1 (8%)		
Age range		***Employment***	
36-45	2 (17%)	Retired	7 (58%)
46-55	2 (17%)	Working	4 (33%)
56-65	4 (33%)	Homemaker with children	1 (8%)
66-75	2 (17%)		
76+	1 (8%)		
Region		***Gave up commitments to care***	
North West	8 (67%)	Yes	5 (42%)
South West	1 (8%)	No	7 (58%)
London	1 (8%)		
South East	1 (8%)	***Have you previously cared for someone else who suffered stroke?***	
East of England	1 (8%)	Yes	1 (8%)
		No	11 (92%)
Relationship with stroke survivor		***Carer's assessment***	
		Yes	4 (33%)
Spouse/partner	9 (75%)	No	7 (58%)
Child	1 (8%)	Don't know	1 (8%)
Parent	2 (17%)		
Length of time caregiving		***Type of assessment***	
		Benefits/financial	1 (8%)
Less than 1 year	2 (17%)	Carers assessment	3 (25%)
1-2 years	6 (50%)	Other	1 (8%)
3-5 years	3 (25%)		
6-8 years	1 (8%)		

Characteristics of the staff

One hundred and one members of staff working in various organisations that support stroke survivors and their families participated in Round 1. Demographic information was not provided by one respondent, so the figures and percentages reported below are for 100 respondents without missing data. As presented in Table 22, most staff were female (n=93, 93%) with most respondents aged between 36 and 45 (n=33, 33%). The largest profession group in Round 1 were physiotherapists (n=42, 42%), followed by occupational therapists (n=31, 31%). Staff employed by a national stroke charity represented 12% (n=12) of the sample. The respondents had a vast amount of experience as over half (n=65, 65%), had been in their role for more than five years. Only six members of staff (6%) had been in their role for less than a year.

Table 22: Characteristics of staff in Round 1

Characteristics	N=100 (%)	Characteristics	N=100 (%)
Gender		***Region***	
Male	7 (7%)	Yorkshire and Humber	6 (6%)
Female	93 (93%)	East Midlands	8 (8%)
		West Midlands	11 (11%)
Profession group		North West	15 (15%)
Nursing	14 (14%)	South West	10 (10%)
Physiotherapists	42 (42%)	London	9 (9%)
Occupational Therapist	31 (31%)	South East	14 (14%)
SLT	1 (1%)	East of England	9 (9%)
National stroke charity staff	12 (12%)	Scotland	17 (17%)
		Other	1 (1%)
Age range		***Length of time in the role***	
18-25	1 (1%)	6 months to less than 1 year	6 (6%)
26-35	24 (24%	1-2 years	10 (10%)
36-45	33 (33%)	3-5 years	19 (19%)
46-55	27 (27%)	6-8 years	21 (21%)
56-65	15 (15%)	9 years or more	44 (44%)

7.4.3 Round 1 responses

Rating the items

As previously described in Chapter 5, the respondents in Round 1 rated 43 items under eight topics on a Likert scale, with 1 being ‘not at all important’ and 5 being ‘extremely important’. The analysis was tabulated to present the total sample number, median, interquartile range (IQR) and the percentage of participants who rated each item 4 and 5 as described in Section 5.6.7 (Chapter 5). Similar information was also tabulated for each cohort (family caregivers and staff). Table 23 provides an example of how the information was tabulated to facilitate decisions on items to proceed to the next round. Items that did not meet the predetermined 70% criterion, as previously described in Chapter 5, are highlighted for easy identification.

Table 23: An example of how the information for each topic was tabulated

TOPIC 7: SUPPORT FOR THE CARER How important is it to ask…										
	Total Sample (N)	Total Sample Median (IQR)	Consensus rate* (%)	Staff (N)	Staff Median (IQR)	Consensus rate* (%)	Family Caregiver s (N)	Family Caregiver s Median (IQR)	Consensus rate* (%)	Criteria**
36)…if the carer feels adequately supported by friends, family members or other social networks?	113	4.0 (1.5)	60	101	4.0 (1.0)	59	12	4.5 (1.8)	67	Not met
37)…if the carer feels adequately supported in their place of work or study? (if appropriate)	113	3.0 (1.0)	47	101	3.0 (1.0)	47	12	4.0 (2.5)	50	Not met
38)…if the carer has received information about the carer support available in their area? (e.g. carers centre, carer support groups)	113	4.0 (1.0)	77	101	4.0 (1.0)	77	12	4.0 (1.0)	75	Met
39)…if the carer feels they are currently getting enough support, or know where to access it when they are ready?	113	5.0 (1.0)	89	101	5.0 (1.0)	89	12	5.0 (1.0)	83	Met
40)…if the carer has received increasing support when the level of care they provide has increased?	113	4.0 (2.0)	71	101	4.0 (2.0)	73	12	4.0 (2.0)	50	Disagree ment

**Consensus rate – Percentage of respondents who rated the item 4 'Very important' or 5 'Extremely important'.*

*** Criteria - If 70% met, retain item, if not met then remove item, if disagreement between cohorts then, re-rate item.*

The analysis in Round 1 showed a high level of consensus on the importance of the items for inclusion in the CAT-S. Twenty out of 43 items were rated equal to or above the median level of 4 (very important) with a consensus level of 70% or above. Ten items did not meet the 70% consensus criteria and were therefore excluded in Round 2. There was disagreement on 13 items between the staff and family caregiver cohorts and these items were included in Round 2 for re-rating (Keeney, Hasson and McKenna, 2006; Knighting et al., 2016). Consequently, 33 items were included in Round 2. The median of each item as rated in Round 1 was used to provide feedback to participants (Hasson, Keeney and McKenna, 2000; Black, 2006). A full list of the 43 items and their rating in Round 1 is presented in Appendix 26.

Ranking of topics

As described in Chapter 5, the participants were asked to rank the eight topics in order of their preference from 1 ‘most important topic’ to 8 ‘least important topic’. Variations were noted on the rankings between the family caregiver and staff cohorts. Staff rated the carer’s health and well-being as their most important topic followed by support for the carer, whereas family caregivers rated support for the carer as their most important topic followed by the carer’s health and well-being. Both staff and family caregivers ranked the topic on ‘End-of-life care and planning’ as their least important topic. The main difference in ranking between the two cohorts appears to be topic 3 (relationship with health and social care professionals), which was ranked seventh by the staff cohort and third by the family caregiver cohort.

Since the items were ranked from first to eighth, the most important item has the lowest mean and the least important item has the highest mean (Knighting et al., 2015). The top-ranked (most important) topic for each cohort has been highlighted in bold (Table 24).

Table 24: Ranking of topics in Round 1

Topic	Total sample ranking Mean (SD)	Staff ranking Mean (SD)	Family caregivers ranking Mean (SD)
Topic 1: Caring situation	4th 3.83 (2.37)	4th 3.76 (2.39)	5th 4.50 (2.23)
Topic 2: Caring role	3rd 3.80 (2.04)	3rd 3.73 (2.08)	4th 4.41 (1.67)
Topic 3: Relationship with health and social professionals	7th 5.74 (1.91)	7th 5.97 (1.75)	3rd 3.83 (2.16)
Topic 4: Respite and emergency care	5th 4.73 (1.73)	5th 4.71 (1.74)	6th 4.91 (1.72)
Topic 5: Financial support and assessments	6th 4.83 (1.90)	6th 4.82 (1.90)	7th 4.91 (1.97)
Topic 6: Carer's health and well-being	**1st 2.67 (1.71)**	**1st 2.65 (1.70)**	2nd 2.91 (1.83)
Topic 7: Support for the carer	2nd 3.44 (1.81)	2nd 3.52 (1.76)	**1st 2.83 (2.16)**
Topic 8: End-of-life and planning	8th 6.92 (1.71)	8th 6.84 (1.77)	8th 7.66 (0.88)

7.5 Delphi Round 2

In view of the low level of participation of family caregivers in Round 1, various strategies were employed to increase the participation of family caregivers in Round 2. This involved attending caregiver events and meetings and talking to staff at the recruitment sites about the importance of the survey to increase the participation of

family caregivers (Keeney, Hasson and McKenna, 2006). Additionally, VAG members participated in raising awareness of the study and subsequently two further sites that did not participate in Round 1 were identified and staff agreed to assist in distributing the questionnaires to family caregivers.

The questionnaire in Round 2 also contained three sections but comprised fewer items than in Round 1 (33 items compared to 43 items). In Round 2, the median group rating given to each of the 33 items in Round 1 was presented to the respondents (whether an item was rated 4 'very important' or 5 'extremely important'). The respondents were invited to consider the median group ratings and then re-rate each item under the eight topics on a five-point Likert scale, as in Round 1. They were also asked to select the most important item under that topic. A comment box was provided to allow participants to express their views if they wished to do so. The respondents were also asked to complete Section B to provide their views on the future CAT-S as well as their demographic data. The survey in Round 2 ran for a period of six weeks from May 2017 to July 2017.

7.5.1 Data analysis

The data analysis for Round 2 replicated Round 1. Descriptive statistics were used to explore the frequencies, median and interquartile range to identify the ratings for each cohort and the total sample for the rating of individual items and ranking of topics (Hasson, Keeney and McKenna, 2000). When utilising the Delphi technique, feedback is normally provided using the median (Black, 2006; Keeney Hasson and McKenna,

2011). The median was therefore used to provide feedback between Round 1 and Round 2 of this study. However, in the Final Round of a Delphi survey, the overall final analysis takes place which furthermore involves calculating the mean of each item as this is used to rank the items in order from 'most important to least important to identify priority items (Keeney, Hasson and McKenna, 2011). In the current study, the overall analysis was conducted at this stage as this was considered to be the last round of the modified Delphi survey. The mean for each item was therefore calculated to allow more specificity for the ranking purposes of the priority items to include in the CAT-S (McDonough et al., 2011; Knighting et al., 2015). Thematic analysis (Braun and Clarke, 2006), as described in Chapter 5, was conducted to analyse data from the open text comments.

7.6 Round 2 findings

The presentation of the findings in Round 2 replicates Round 1. Additionally, as stated earlier in this chapter, findings from the open text comment boxes and the respondents' views on the CAT-S in the first part of Section B of the questionnaire (both rounds) will be presented together to avoid repetition.

7.6.1 Response rate

Family caregivers

As in Round 1, it is impossible to reliably state how many family caregivers received the questionnaire due to the reliance on gatekeepers and online advertisement. The number of paper questionnaires that were distributed in Round 2 has been used to

calculate an approximate response rate for the family caregiver cohort in this round. A total of 250 paper questionnaires were distributed to the five recruitment sites as in Round 1 plus the additional two sites in Round 2. Family caregivers were encouraged to take part regardless of whether they participated in Round 1 or not. Seventeen paper questionnaires were returned via post and two were completed online resulting in a total of 19 respondents in Round 2. The response rate for this round was calculated to be 7.6%.

Staff

For the staff cohort, the figures provided by the recruiting organisations were once again utilised to calculate an approximate response rate. Invitation emails were sent out to the same recruiting organisations as in Round 1 via gatekeepers to approximately 1,653 members of staff. The online questionnaire was completed by 117 respondents. The response rate for the staff cohort was calculated to be 7.1% in Round 2. Delphi surveys are notorious for their response rates lowering as the rounds increase (McKenna, 1994; Keeney, Hasson and McKenna, 2006). However, the slight increase of participants in Round 2 of this survey can be partly explained due to logistical challenges which were reported by gatekeepers in some of the recruiting organisations in Round 1 (invitation emails sent late), which were not reported in Round 2.

7.6.2 Participants

Characteristics of family caregivers

In Round 2, the questionnaire was completed by 19 family caregivers. Like in Round 1, the respondents in this round were also predominantly female (n=16, 84%). All family caregivers described themselves as White - English, except one who reported 'other' but did not state their ethnicity. As illustrated in Table 25, over half of family caregivers (n=11, 58%) were aged above 56. The respondents originated from various regions across the UK but were mostly from the North West of England (n=8, 42%) closely followed by the South West of England (n=7, 37%) whilst the remaining respondents were from the North East and South East of England. One respondent selected 'other' but did not disclose which region they were from. Sixteen family caregivers (84%) were either a spousal family caregiver or providing support to their partner while the remaining three were caring for a parent. All but three (16%) were established family caregivers (had been providing care for over a year).

Just over half (n=10, 53%) reported that they were providing care around the clock (24 hours a day). Most were retired (n=8, 42%), three (16%) were working and supporting their own children at the same time, whereas others had additional demands on their time including studying and supporting grandchildren. Nearly half (n=9, 47%) had given up other commitments to provide care. Seventeen (92%) were providing care to a stroke survivor for the first time, whereas the other two (8%) had previous experience of caring for a stroke survivor. Less than half (n=8, 42%) admitted to having completed a carer's assessment, whereas the remainder reported having not completed one or were uncertain.

Table 25 : Characteristics of family caregivers in Round 2

Characteristics	Round 2 N=19 (%)	Characteristics	Round 2 N=19 (%)
Gender		***Hours of caregiving per week***	
Male	3 (16%)	11-20	1 (5%)
Female	16 (84%)	21-30	2 (11%)
		31-40	5 (26%)
Ethnicity		24 hours a day	10 (53%)
White - English	18 (95%)	Other	1 (5%)
Other	1 (5%)		
Age range		***Employment***	
26-35	1 (5%)	Unemployed	3 (16%)
36-45	3 (16%)	Retired	8 (42%)
46-55	4 (21%)	Working	3 (16%)
56-65	4 (21%)	Homemaker with children	3 (16%)
66-75	7 (37%)	Study	1 (5%)
		Other	1 (5%)
Region		***Gave up commitments to care***	
North East	2 (11%)	Yes	9 (47%)
North West	8 (42%)	No	10 (53%)
South West	7 (37%)		
South East	1 (5%)		
Other (specify)	1 (5%)		
		Have you previously cared for someone else who suffered stroke?	
		Yes	2 (11%)
		No	17 (89%)
Relationship with stroke survivor		***Carer's assessment***	
		Yes	8 (42%)
Spouse/partner	16 (84%)	No	6 (32%)
Parent	3 (16%)	Don't know	5 (26%)
Length of time caregiving		***Type of assessment***	
		Benefits/financial	3 (16%)
Less than 1 year	3 (16%)	Carers Assessment	7 (37%)
1-2 years	6 (32%)	Other	1 (5%)
3-5 years	5 (26%)	Not stated	8 (42%)
6-8 years	1 (5%)		
9 years or more	4 (21%)		

Characteristics of the staff panel

One hundred and seventeen staff participated in Round 2, however, only 110 respondents provided their demographic information. The vast majority were female

(n=107, 93%). One participant did not submit their answer to this question. Physiotherapists remained the largest profession group (n=39, 33%) as in Round 1, followed by nurses (n=28, 25%). In Round 2, the number of respondents in the 36-45 and 46-55 age groups was almost the same at 34% and 33%, respectively. Like in Round 1, there was a wide distribution with regard to the work location of the staff, as illustrated in Table 26. Most of the respondents were experienced staff as 58% (n=64) had been in their role for over 9 years.

Table 26: Characteristics of staff in Round 2

Characteristics	Round 2 N=110 (%)	Characteristics	Round 2 N=110 (%)
Gender		***Region***	
Male	2 (2%)	North East	4 (4%)
Female	107 (97%)	Yorkshire and Humber	6 (5%)
Missing	1 (1%)	East Midlands	7 (6%)
		West Midlands	5 (5%)
Profession group		North West	15 (14%)
Nursing	28 (25%)	South West	10 (9%)
Physiotherapists	39 (35%)	London	4 (4%)
Occupational Therapist	27 (25%)	South East	7 (6%)
SLT	12 (11%)	East of England	7 (6%)
National stroke charity staff	3 (3%)	Scotland	42 (38%)
		Wales	1 (1%)
Other	1 (1%)	Other	2 (2%)
Age range		***Length of time in role***	
26-35	14 (13%)	6 months to less than 1yr	3 (3%)
36-45	37 (34%)	1-2 years	12 (11%)
46-55	36 (33%)	3-5 years	14 (13%)
56-65	22 (20%)	6-8 years	17 (15%)
66-75	1 (1%)	9 years or more	64 (58%)

7.6.3 Round 2 responses

Rating items

In Round 2, the respondents rated 33 items under eight topics using the same Likert

scale as in Round 1. The consensus criterion applied to items in Round 1, as discussed in Chapter 5, was replicated in Round 2. Out of the 33 items, 15 were equal to or above the median level of 4 (very important) with a consensus level of 70% or above. There was disagreement on 15 items between the staff and family caregiver cohorts and as a result these items had to be included for re-rating. Three items did not meet the pre-determined criteria and were therefore excluded. The analysis in Round 2 resulted in 30 items. The full Round 2 analysis is presented in Appendix 27. The exclusion of items not meeting the predetermined criteria in Round 1 and Round 2 resulted in changes to the number of items in each topic. A summary of the changes that occurred between Round 1 and Round 2 is provided in Table 27. No new items were suggested or added between the rounds.

Table 27: Changes to the number of items between Round 1 and Round 2

Topic	R1 number of items	R1 change	R2 number of items	R2 change
Topic 1 Caring situation	7	(-2)	5	0
Topic 2 Caring role	8	(-1)	7	0
Topic 3 Relationship with health and social care professionals	3	0	3	(-1)
Topic 4 Respite and emergency care	3	0	3	(-1)
Topic 5 Financial support and assessments	7	(-2)	5	(-1)
Topic 6 Carer's health and well-being	7	(-3)	4	0
Topic 7 Support for the carer	5	(-2)	3	0
Topic 8 End-of-life and planning	3	0	3	0
Total number of items	43	(-10)	33	(-3)

Since this round was considered as the final round as previously discussed in Section 7.5.1 of this chapter, the overall analysis was undertaken at this stage. This involved calculating the mean in addition to the median, which was used to give feedback to respondents between Round 1 and Round 2 (Hasson, Keeney and McKenna, 2000). The mean for each item was therefore calculated in both cohorts (staff and family caregivers) and the total sample. The total sample mean was therefore used to rank the items from the most important to the least important, thus allowing the top 10 items for inclusion in the CAT-S to be determined (Keeney, Hasson and McKenna, 2011). The rationale for having 10 items was based on the original CAT (Knighting et al., 2015) and pragmatic to avoid overburdening staff and family caregivers when completing the CAT-S. Table 28 provides a summary of the final 30 items in Round 2 as ranked by the total sample mean. As all items had been rated by the participants, the consensus level for each item is also reported in the table. The top 10 items ranked by the family caregiver and staff cohorts are presented in Appendix 30 and 31.

Table 28: Final 30 items ranked by the total sample mean

Rank	Item	Topic* (R1 item number)	N	Consensus rate** (%)	Mean (SD)
1	To ask if the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, caring for grandchildren)	1 (4)	136	90	4.64 (.70)
2	To ask if the carer feels able to manage and cope with the behaviour of the person they care for?	2 (12)	136	93	4.64 (.61)
3	To ask if the carer needs any training to provide care safely, such as lifting, and handling or equipment use training?	2 (9)	136	91	4.58 (.64)
4	To ask if the carer requires support to provide personal care (including toileting, washing and dressing, feeding) to the person that they care for?	2 (10)	136	90	4.57 (.69)

5	To ask if the carer feels able to support the psychological or emotional needs of the person they care for?	2 (13)	136	90	4.54 (.67)
6	To ask if the carer has a named person or number to call with any concerns about the person they care for?	2 (15)	136	90	4.54 (.67)
7	To ask if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	4 (21)	136	89	4.54 (.68)
8	To ask if the carer understands the expected recovery from stroke for the person they are caring for?	1 (5)	136	88	4.50 (.76)
9	To ask if the carer is accessing any of the support or assistance available to carers?	1 (7)	136	87	4.47 (.74)
10	To ask if the carer has responsibility for making decisions about the care of the person they care for, as a result of the stroke?	1 (6)	136	86	4.41 (.78)
11	To ask if the carer feels they are currently getting enough support, or know where to access it when they are ready?	7 (39)	136	87	4.41 (.78)
12	To ask if the carer would like help to cope with any aspects of their caring role?	6 (31)	136	86	4.36 (.71)
13	To ask if the carer is able to balance their own health needs with the demands of caring?	6 (33)	136	83	4.32 (.76)
14	To ask if the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break?	4 (19)	136	85	4.30 (.74)
15	To ask if the carer feels that professionals involve them in decision-making by seeking their knowledge and expertise about the care needed by the person they care for?	3 (18)	136	84	4.29 (.75)
16	To ask if the carer feels they are receiving the support they need from professionals at the time they need it?	3 (17)	136	86	4.28 (.73)
17	To ask if the carer needs support to assist with any aspect of the rehabilitation of the person they care for?	2 (11)	136	80	4.26 (.78)
18	To ask if the carer lives in the same house as the person they care for?	1 (2)	136	75	4.22 (.89)
19	To ask if the carer knows of and has applied for all appropriate funding such as benefits, mobility schemes?	5 (23)	136	84	4.22 (.70)
20	To ask if the carer knows the wishes and preferences of the person they care for and they have been written down and shared e.g. Advance Care Planning (ACP) document?	8 (41)	136	82	4.21 (.77)

21	To ask if the carer would like to talk to someone about their emotional well-being?	6 (30)	136	78	4.16 (.78)
22	To ask if the carer has had a carer's assessment?	5 (27)	136	77	4.13 (.77)
23	To ask if the carer has received increasing support when the level of care they provide has increased?	7 (40)	136	78	4.08 (.76)
24	To ask if the carer needs advice on any legal matters? (e.g. arranging power of attorney)	8 (43)	136	73	4.04 (.85)
25	To ask if the carer is supporting the person they care for with their medications?	2 (8)	136	57	4.03 (.92)
26	To ask if the carer has any financial worries?	5 (22)	136	71	4.03 (.80)
27	To ask if the carer knows what support is available to them before and after the death of the person that they care for?	8 (42)	136	74	4.03 (.83)
28	To ask if the carer has received information about the carer support available in their area? (e.g. carers centre, carer support groups)	7 (38)	136	77	4.01 (.73)
29	21. To ask if the carer knows what a carer's assessment is?	5 (26)	136	73	3.99 (.85)
30	24. To ask if the carer would like to talk to someone about their own physical well-being?	6 (29)	136	73	3.95 (.74)

**Topic 1- Caring situation, Topic 2- Caring situation, Topic 3 - Relationship with health and social care professionals, Topic 4 - Respite and emergency care, Topic- 6 Carer's health and well-being, Topic 7- Support for the carer, Topic 8 - End of life and planning.*

***Consensus rate – percentage of the total sample who rated the item 4 'Very important' or 5 'Extremely important'*

Ranking of topics

The respondents were similarly asked to rank the topics in order of preference for inclusion in the CAT-S from 1 (most important) to 8 (least important) in this round. It is interesting to note that family caregivers and staff ranked the topics as the same in this round. As illustrated in Table 29, the only difference was in Topic 4 and Topic 5. Staff rated respite and emergency care as their fifth choice, whereas the family caregivers prioritised financial support and assessments by rating them as their fifth choice over respite and emergency care which they rated sixth.

Some changes were also noted between Round 1 and Round 2 on how the topics were ranked by each cohort and the total sample. In Round 1, the top two ranked topics were focused on family caregivers (Topic 6: Carer's health and well-being, and Topic 7: Support for the carer). However, in Round 2, rather than both the top two topics being focussed on family caregivers, the first topic was focused on family caregivers (Topic 6: Carer's health and well- being) and the second topic on the caring situation itself (Topic 2: Caring situation) suggesting more balance in the ranking across the topics in Round 2. As in Round 1, the most important item has the lowest mean. The most important topic in each cohort and the total sample is marked in bold (Table 29).

Table 29: Ranking of topics in Round 2

Topic	Total sample ranking Mean (SD)	Staff ranking Mean (SD)	Family caregivers ranking Mean (SD)
Topic 1 Caring situation	2nd 2.68 (1.69)	2nd 2.67 (1.71)	2nd 2.78 (1.58)
Topic 2 Caring role	3rd 3.02 (1.20)	3rd 2.98 (1.14)	3rd 3.26 (1.52)
Topic 3 Relationship with health and social professionals	7th 6.11 (1.61)	7th 6.19 (1.58)	7th 5.68 (1.79)
Topic 4 Respite and emergency care	5th 5.38 (1.31)	5th 5.37 (1.23)	6th 5.47 (1.74)
Topic 5 Financial support and assessments	6th 5.54 (1.46)	6th 5.63 (1.41)	5th 5.00 (1.66)
Topic 6 Carer's health and well-being	**1st 1.93 (1.44)**	**1st 1.87 (1.39)**	**1st 2.26 (1.72)**
Topic 7 Support for the carer	4th 3.86 (1.42)	4th 3.89 (1.40)	4th 3.73 (1.55)
Topic 8 End of life and planning	8th 7.44 (1.26)	8th 7.38 (1.34)	8th 7.78 (0.53)

7.7 Participants' views on the development and future use of the CAT-S

In the first part of Section B of the questionnaire (both rounds), the respondents' views were sought on the development and future use of the CAT-S. They were asked questions relating to the importance and frequency of identifying the needs of family caregivers. Furthermore, the respondents were invited to state their preferred profession groups to complete the CAT-S with stroke family caregivers.

When asked to rate the importance of identifying the needs of family caregivers on a Likert scale 1 'not at all important' to 5 'extremely important', staff and family caregivers in Round 1 and Round 2, overwhelmingly rated the importance as 'very important' or 'extremely important' (Round 1: family caregivers n=11 (92%), staff n=96 (96%) Round 2: family caregivers n=14 (73%), staff n=102 (87%) respectively). Seven respondents from the staff cohort and two from the family caregiver cohort did not provide a response to this question in Round 2. However, it is important to note that none of the respondents in either round felt that this was not an important subject.

Recognising that caring situations may change over time, the respondents were asked how often they felt the needs of stroke family caregivers should be reviewed or identified as a minimum. In Round 1, five family caregivers (42%) and 38 staff (38%) identified every three months as the minimum timeframe to have their needs identified. This was followed by every six months in both cohorts, family caregivers n=4 (33%) and staff n=24 (24%) respectively. Twelve (12%) staff and one family caregiver

selected ‘other’ and stated that the needs of family caregivers should be identified regularly immediately after hospital discharge and at any point as requested by the caregiver. In Round 2, the majority of staff (n=90, 83%) identified the same period (six months or less) as the family caregivers (n=13, 68%) as the frequency for family caregivers to have their needs assessed. Three family caregivers (16%) and 13 staff (12%) selected ‘other’ and specified that the frequency should be agreed with the family caregiver, some suggested on each home visit conducted by any health and social care professional while others proposed that this could be part of the annual review by the GP.

Preferred staff to complete the CAT-S

In both rounds, the respondents were asked to identify their preferred profession group to complete the CAT-S with stroke family caregivers. In Round 1, the top three profession groups as identified by the family caregiver cohort were General Practitioners (GP) (n=10, 83%), national stroke charity staff (n=8, 67%) and community therapists (n=7, 58%). Staff identified social workers (n=76, 76%), community therapists (n=73, 73%) and national stroke charity staff (n=61, 61%) as their top three preferred profession groups or staff to complete the CAT-S. As illustrated in Table 30, the top three profession groups identified by the family caregivers in Round 2 are the same as those identified in Round 1. A slight difference was, however, noted in the staff cohort. In Round 2, the staff identified the patient’s treating team amongst their top three preferred groups instead of staff from a national stroke charity as in Round 1. The top three preferred profession groups or staff as

identified by each cohort are highlighted in bold in Table 30.

Table 30: Preferred profession groups or staff to complete the CAT-S with family caregivers

Profession group /role	Round 1		Round 2	
	Family caregivers N=12 (%)	Staff N=100 (%)	Family caregivers N=19 (%)	Staff N=110 (%)
GP	10 (83)	51 (51)	13 (68)	58 (53)
Practice nurse	3 (25)	38 (38)	6 (32)	51 (46)
District nurse	2 (17)	52 (52)	4 (21)	58 (53)
Community nurse	0 (0)	41 (41)	2 (11)	32 (29)
Social worker	2 (17)	76 (76)	10 (53)	72 (65)
National Stroke Charity staff	8 (67)	61 (61)	16 (84)	63 (57)
Staff involved in patients' treatment	5 (42)	54 (54)	11 (58)	73 (66)
Carer Centre staff	1 (8)	44 (44)	10 (53)	47 (43)
Community therapists	7 (58)	73 (73)	13 (68)	78 (71)
Anyone who has contact with carers	3 (25)	48 (48)	10 (53)	50 (45)
Other	0 (0)	14 (14)	2 (11)	15 (14)

7.8 Open text comments

In this section, the findings from the open text comments section in Round 1 and Round 2 will be presented. Comments from family caregivers and staff are presented separately. Direct quotations from the questionnaire will be used to provide examples of the participants' comments. Unique identification numbers that were assigned to the respondents during the data analysis will be used to identify respondents. Comments

from family caregivers will be labelled as follows: Family caregiver identification number and Delphi round Family caregiver 03-R1) and staff: Staff identification number and Delphi round (Staff 10-R2).

7.8.1 Comments from stroke family caregivers

Eight respondents in Round 1 and 12 in Round 2 submitted their comments in the open text section of the questionnaire. There were very few comments provided by the respondents under each topic to allow conclusions to be made for each topic. Additionally, some topics did not have any comments. However, three themes were identified from the overall comments made by family caregivers in both rounds namely the importance of items and topics, challenges experienced during caregiving and suggestions made by the family caregivers.

Importance of the CAT-S items and topics

Although most of the comments were very brief, the value of the CAT-S items was emphasised by family caregivers. Most commented that the proposed items and topics are important and meaningful to stroke family caregivers as stated by one respondent:

> *'I think all of these questions mean something to the carers' Family caregiver 05-R1.*
>
> *'The topics are very important for carers' Family caregiver 13-R2.*

Challenges encountered during caregiving

Another theme identified were the challenges that family caregivers themselves experienced during their caregiving role. Although the open comments sections of the

questionnaire did not directly request information regarding their experiences, most family caregivers stated the various challenges that they seemed to have experienced in their role such as lack of information about medication on discharge from hospital:

> *'When my husband came home from hospital, I had no idea about new medication, staff offered no advice until three days after his discharge he had been put on warfarin which I found should have meant at least a leaflet' (Family caregiver 7-R2).*

It was evident from the comments made by most family caregivers that adjusting to the caregiving role was a challenge that they had experienced. Most commented on how the sudden nature of stroke resulted in individuals assuming the caregiving role with minimal preparation as suggested by one respondent:

> '*Care is the first job I ever had that required no interview, no training, no pay and instant start!!! It's very hard to stay positive every day' (Family caregiver 15-R2).*

Other family caregivers shared the challenges that they experienced with their own emotions particularly seeing their loved ones unable to complete tasks that they could complete prior to the stroke. Most reported feeling frustrated and unsupported in their caregiving role:

> *'Carers left to get on with things can be emotionally draining watching loved ones try to cope' (Family caregiver 19-R2).*

For respondents who were employed and caring at the same time, they cited some physical challenges that they experienced such as exhaustion as a result of the combining work and being a caregiver:

'Very difficult physically exhausting looking after someone with family plus work. There is no middle ground-one minute your life is your own the next you have another full-time job' (Family caregiver 10-R1).

Recommended support

From the comments, the respondents appeared to be offering recommendations or suggestions regarding the support that they received and found to be useful. These included talking to friends and family while others emphasised the importance of belonging to a peer support group:

'It is important to belong to a group such as [national stroke charity] peer support meetings where helpful views are exchanged' (Family Caregiver 14 - R2).

Some family caregivers highlighted the support that they wished they had received to allow them to better manage in their caregiving role. Most commented on the importance of having counselling services to allow them to cope:

'*Carer counselling or coping advice should be offered on regular basis' (Family Caregiver 04-R1).*

Some respondents offered their thoughts on how to improve the support provided to stroke family caregivers. The suggestions included having a single review for the stroke survivor and the family caregiver, completing the CAT-S electronically, and conducting regular telephone follow up for family caregivers:

'People involved with each particular stroke person could have a CAT- S on their computer system which would the flag up when a review is needed - a phone call to the carer would be all that was needed' (Family caregiver 13-R2).

7.8.2 Comments from staff

Forty-eight staff in Round 1 and 39 in Round 2 provided their comments across the two rounds of the Delphi survey. Similar to the family caregivers' comments, staff did not provide comments specific to each of the eight topics under which the items were presented, however, three themes were identified across the staff comments in both rounds of the survey, namely comments regarding the CAT-S, staff perceptions about their practice and identified concerns.

Comments regarding the CAT-S

Various comments regarding the items on CAT-S were provided by the respondents. There appeared to be a consensus among most staff that the proposed items for inclusion in the CAT-S were relevant and valid and no further topics or items were suggested by staff. One respondent shared the following:

> *'All are very valid and extremely important in my opinion' (Staff 5 –R1).*

Although the items were relevant, most respondents highlighted some difficulties particularly in prioritising the most important topics and items for inclusion in the CAT-S due to the differences in individual circumstances:

> *'Very difficult to prioritise as each patient and carer have individual needs and problems' (Staff 47-R2).*

Another respondent suggested:

> *'All are important it's not easy to choose the most important as that would depend on the relevance to the carer!' (Staff 86-R1).*

Staff also provided comments relating to the usability of the CAT-S in practice. The focus of the comments was about ensuring that the CAT-S tool was easy to complete and not lengthy to minimise burdening both staff and family caregivers. A respondent shared the following:

> *'I feel that the tool needs to be as short as possible as there is often so much paperwork to deal with when someone is discharged home to the community following a stroke' (Staff 99-R1).*

Another comment was:

> *'Please don't make the form too long and arduous to complete! Carers have enough to contend with' (Staff 77-R1).*

Staff perceptions regarding their own practice

From the comments, it appears that completing the questionnaire prompted staff to reflect on their own practice and challenge their perceptions in relation to how they provide support to family caregivers. Some participants reflected on their practice in relation to the provision of information to family caregivers within their services while others highlighted the lack of caregiver involvement in decision-making and the high expectations that they have from family caregivers:

> *'I think this is something we misjudge often - we give limited information over the phone, we aren't always brilliant at involving carers in decisions, and then we expect them to resume their care duties on discharge. We should definitely be involving carers more while the patient is in hospital' (Staff 50 - R1).*

For other respondents completing the questionnaire provided an opportunity not only to reflect on their services but further assisted them with forward planning to improve

the support offered to family caregivers:

> *'Our stroke reviewers service no longer exists at the 6-month point. This survey makes me wonder about the impact that this will have on the carers' longer term. This survey has made me consider gathering a wider range of information for my carers to access more readily' (Staff 7-R2).*

Identified concerns

Staff expressed concerns regarding some of the proposed items for inclusion in the CAT-S particularly if they felt that they could not be responsive to the needs of the family caregivers due to the absence of services such as those offering psychological support in their local areas:

> *'I would also have concerns about asking carers about things we don't have enough resources to help them with. For example, psychological support is in very short supply in our area. If this is highlighted as a need where would I be able to direct an individual to' (Staff 5-R1).*

Another staff member commented:

> '*All of these questions are important, but quite unhelpful if there is no support to be offered to the carer, should they identify a need. Very common situation at this time' (Staff 44-R2).*

The availability of services providing respite to family caregivers was highlighted as a concern by the respondents. Most commented on the unavailability and sustainability of respite services in their areas, whilst others were concerned about the limited options available to family caregivers:

'More resources need to be available to enable carers to take a break from their caring

role. Carer services are not very cohesive, and many projects are at the mercy of funding constraints. Projects are often short-lived and poorly promoted' (Staff 94 R2).

7.9 Final 16 items

The number of family caregivers in Round 2 remained considerably low in comparison to staff (19 family caregivers versus 117 staff). A third Delphi round was considered, however, in view of the low participation of family caregivers in Round 1 and Round 2, a decision was taken not to conduct a third round. As discussed in Section 5.6.6 (Chapter 5), there are no strict criteria regarding the number of Delphi rounds (Hasson, Keeney and McKenna, 2000, 2011). Additionally, time was required in this study to allow consultation with VAG members to further refine the CAT-S items as part of the action research process. Furthermore, since the current study was conducted as part of an academic degree, conducting a third round required consideration of time and financial constraints. Studies using the modified Delphi technique consisting of two rounds have been reported by other authors (McDonough et al., 2011; Knighting et al., 2015).

A review of the top 10 items ranked by mean in each cohort (family caregivers and staff) was undertaken at this stage. This was done to ensure equal consideration was given to hearing the views of both groups. As illustrated in Appendix 30 (family caregivers' cohort) and Appendix 31 (staff cohort), it was noted that seven items were top ranked by staff and family caregivers (Topic 1: two items, Topic 2: four items, Topic 4: one item). For the remaining three items, family caregivers selected items from topic 3 (Relationship with health and social care professionals, two items) and topic 7

(support for the carer, one item). Staff on the other hand selected items from topic 1 (caring situation, two items) and topic 2 (caring role, one item).

Furthermore, a review of the top 10 items ranked by the total sample mean (Table 31), revealed that five items originated from topic 2 (caring situation), four originated from topic 1 (caring role) and one from topic 4 (respite and emergency care). Therefore, in accordance with the processes followed during the development of the original CAT (Knighting et al., 2015) an inclusive approach was similarly, adopted for this study to ensure the inclusion of items from all the eight topics. This involved selecting the top two items ranked according to total sample mean under each of the eight topics resulting in 16 items (Table 32). The ranking by total sample mean under each of the eight topics is presented in Appendix 32. The 16 items were sent to the expert panel for further refinement. The two-round modified Delphi survey in the current study was staff led, as more staff than family caregivers participated. Therefore, choosing the top two items under each topic enabled the ‘voices’ of the stroke family caregivers to be retained as the plan was to have the same number of staff and family caregivers during the expert panel consultation.

Table 31: Top 10 items ranked by the total sample mean in Round 2

Rank	Items	Topic* (R1 item number)	N	Consensus rate** (%)	Mean (SD)
1	To ask if the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, caring for grandchildren)	1 (4)	136	90	4.64 (.70)
2	To ask if the carer feels able to manage and cope with the behaviour of the person they care for?	2 (12)	136	93	4.64 (.61)
3	To ask if the carer needs any training to provide care safely, such as lifting, and handling or equipment use training?	2 (9)	136	91	4.58 (.64)
4	To ask if the carer requires support to provide personal care (including toileting, washing and dressing, feeding) to the person that they care for?	2 (10)	136	90	4.57 (.69)
5	To ask if the carer feels able to support the psychological or emotional needs of the person they care for?	2 (13)	136	90	4.54 (.67)
6	To ask if the carer has a named person or number to call with any concerns about the person they care for?	2 (15)	136	90	4.54 (.67)
7	To ask if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	4 (21)	136	89	4.54 (.68)
8	To ask if the carer understands the expected recovery from stroke for the person they are caring for?	1 (5)	136	88	4.50 (.76)
9	To ask if the carer is accessing any of the support or assistance available to carers?	1 (7)	136	87	4.47 (.74)
10	To ask if the carer has responsibility for making decisions about the care of the person they care for, as a result of the stroke.	1 (6))	136	86	4.41 (.78)

**Topic 1- Caring situation, Topic 2- Caring role, Topic 4.*

*** Consensus rate - Percentage of respondents who rated the item 4 'Very important' or 5 'Extremely important'*

Table 32: 16 Highest ranked items per topic (total sample mean) – Round 2

Rank	Item	Topic* (R1 item number)	N	Consensus rate** (%)	Mean (SD)
1	To ask if the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, caring for grandchildren)	1 (4)	136	90	4.64 (.70)
2	To ask if the carer understands the expected recovery from stroke for the person they are caring for?	1 (5)	136	88	4.50 (.76)
3	To ask if the carer feels able to manage and cope with the behaviour of the person they care for?	2 (12)	136	93	4.64 (.61)
4	To ask if the carer needs any training to provide care safely, such as lifting, and handling or equipment use training?	2 (9)	136	91	4.58 (.64)
5	To ask if the carer feels that professionals involve them in decision-making by seeking their knowledge and expertise about the care needed by the person they care for?	3 (18)	136	84	4.29 (.75)
6	To ask if the carer feels they are receiving the support they need from professionals at the time they need it?	3 (17)	136	86	4.28 (.73)
7	To ask if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	4 (21)	136	89	4.54 (.68)
8	To ask if the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break?	4 (19)	136	85	4.30 (.74)
9	To ask if the carer knows of and has applied for all appropriate funding such as benefits, mobility schemes?	5 (23)	136	84	4.22 (.70)
10	To ask if the carer has had a carer's assessment?	5 (27)	136	72	4.13 (.77)
11	To ask if the carer would like help to cope with any aspects of their caring role?	6 (31)	136	86	4.36 (.71)
12	To ask if the carer is able to balance their own health needs with the demands of caring?	6 (33)	136	83	4.32 (.76)
13	To ask if the carer feels they are currently getting enough support, or know where to access it when they are ready?	7 (39)	136	87	4.41 (.71)
14	To ask if the carer has received increasing support when the level of care they provide has increased?	7 (40)	136	80	4.08 (.76)
15	To ask if the carer knows the wishes and preferences of the person they care for and they have been written down and shared e.g. Advance Care Planning (ACP) document?	8 (41)	136	82	4.21 (.77)
16	To ask if the carer needs advice on any legal matters? (e.g. arranging power of attorney)	8 (43)	136	73	4.04 (.85)

***Topic 1 - Caring situation, Topic 2 - Caring situation, Topic 3 - Relationship with health and social care professionals, Topic 4 - Respite and emergency care, Topic 5 - Financial support and assessments, Topic 6 - Carer's health and well-being, Topic 7 - Support for the carer, Topic 8 - End of life and planning. *Consensus rate- percentage of respondents who rated the item 4 'Very important' or 5 'Extremely important'*

7.10 Consultation with an expert panel

As part of the action research process and to further refine the CAT-S items, a consultation was undertaken with an expert panel. As previously described in Section 5.6.8 (Chapter 5) the panel consisted of nine members of the VAG and three additional stroke family caregivers (six staff and six family caregivers in total). However, only 11 members finally took part in the consultation (staff n=5, stroke family caregivers n=6) as one panel member (staff) became unwell during the consultation period and was unavailable to participate. A short questionnaire was developed using the 16 highest ranked items across the eight domains as presented in Table 32. The panel was asked to rank their top 10 items from the list and were further invited to provide comments or highlight any issues that they felt were missing.

7.10.1 Data analysis

Since this was a ranking exercise, the mean for each item was therefore calculated to allow more specificity for ranking the priority items to include in the CAT-S (McDonough et al., 2011; Knighting et al., 2015). Open text responses from the comment sections were subjected to thematic analysis as previously described in Chapter 5.

7.11 Expert panel findings

7.11.1 Top 10 ranked items

Members of the expert panel ranked their top 10 items from a list of 16 items that were identified following the final analysis in Round 2. Items were ranked ‘1’ as the highest

ranked item, so the items ranked highest have the lowest mean (Keeney, Hasson and McKenna, 2011; Knighting et al., 2015). A list of the top 10 items according to mean as ranked by the expert panel is presented in Table 33. Since respondents were asked to rank and not rate the items, there is no consensus level provided in Table 33. The number of respondents who ranked each item is provided. Items that were not rated among the top 10 by the expert panel are highlighted in Table 33 for easy identification.

Table 33: Top 10 items ranked by the total sample mean (expert panel).

Rank	Items	Topic* (R1 item number)	N	Mean (SD)
1	…if the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, caring for grandchildren)	1 (4)	7	3.28 (3.19)
2	…if the carer feels able to manage and cope with the behaviour of the person they care for?	2 (12)	9	3.77 (2.58)
3	…if the carer understands the expected recovery from stroke for the person they are caring for?	1 (5)	9	4.22 (3.07)
4	…if the carer would like help to cope with any aspects of their caring role?	6 (31)	2	4.50 (3.53)
5	…if the carer needs any training to provide care safely, such as lifting, and handling or equipment use training?	2 (9)	5	5.20 (2.16)
6	…if the carer has had a carer's assessment?	5 (27)	9	5.33 (4.03)
7	…if the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break?	4 (19)	5	5.40 (1.94)
8	…if the carer feels they are receiving the support they need from professionals at the time they need it?	3 (17)	7	5.42 (2.76)
9	…if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	4 (21)	10	5.60 (2.54)
10	…if the carer feels that professionals involve them in decision-making by seeking their knowledge and expertise about the care needed by the person they care for?	3 (18)	9	5.77 (3.52)
11	…if the carer is able to balance their own health needs with the demands of caring?	6 (33)	9	5.88 (2.71)
12	…if the carer feels they are currently getting enough support, or know where to access it when they are ready?	7 (39)	7	6.42 (2.82)
13	…if the carer knows of and has applied for all appropriate funding such as benefits, mobility schemes?	5 (23)	8	6.50 (2.39)
14	…if the carer knows the wishes and preferences of the person they care for and they have been written down and shared e.g. Advance Care Planning (ACP) document?	8 (41)	4	6.75 (1.70)
15	…if the carer has received increasing support when the level of care they provide has increased?	7 (40)	4	7.50 (1.73)
16	…if the carer needs advice on any legal matters? (e.g. arranging power of attorney).	8 (43)	6	7.83 (2.13)

**Topic 1 - Caring situation, Topic 2 - Caring situation, Topic 3 - Relationship with health and social care professionals, Topic 4 - Respite and emergency care, Topic 5 - Financial support and assessments, Topic 6 - Carer's health and well-being, Topic 7 - Support for the carer, Topic 8 - End of life and planning.*

7.11.2 Comments from the open text section

The short comments from the questionnaire completed by the expert panel were reviewed, and although some members felt that the list was comprehensive, the majority provided comments to suggest that other important topics were missing from the list particularly regarding emotional support for the family caregivers. Comments from a staff panel member were:

> *'It covers a good range of topics, but I don't think there is much emphasis regarding the emotional support that the carers would require' (Staff panel member-4).*

In highlighting the loneliness experienced by family caregivers, a panel member who was supporting her husband following stroke highlighted:

> *'Life becomes very lonely when the personality of your life partner is changed by stroke damage. There could perhaps be some guidance as to where to get support with this' (Family caregiver panel number 3).*

7.11.3 Final review of the CAT-S items

The findings from the consultation exercise with the expert panel were shared with VAG members and discussed with members of the supervisory team. An unexpected finding from the modified Delphi survey was the absence of the item on emotional support for family caregivers which was strongly expressed by participants during the interviews in the exploratory phase but was not rated highly in the survey. Since emotional support was identified as a missing item during the consultation with the expert panel and was highlighted in the literature review (Chapter 2), a decision was made to include an item relating to emotional support for caregivers on the CAT-S for

the pilot. Additionally, a decision was taken to retain the item regarding end-of-life planning which is present on the original CAT but was not highly rated in the current study. This decision was based on guidance from key national stroke guidelines on the support for individuals affected by stroke and their family caregivers (DH, 2007; NICE, 2008; ISWP, 2012, 2016). This resulted in 12 items for inclusion in the CAT-S (Table 34).

Table 34: Final 12 CAT-S items for pilot

Rank	Item	Topic* (R1 item number)
1	…if the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, caring for grandchildren)	1 (4)
2	…if the carer feels able to manage and cope with the behaviour of the person they care for?	2 (12)
3	…if the carer understands the expected recovery from stroke for the person they are caring for?	1 (5)
4	…if the carer would like help to cope with any aspects of their caring role?	6 (31)
5	…if the carer needs any training to provide care safely, such as lifting, and handling or equipment use training?	2 (9)
6	…if the carer has had a carer's assessment?	5 (27)
7	…if the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break?	4 (19)
8	…if the carer feels they are receiving the support they need from professionals at the time they need it?	3 (17)
9	…if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	4 (21)
10	…if the carer feels that professionals involve them in decision making by seeking their knowledge and expertise about the care needed by the person they care for?	3 (18)
Not ranked	if the carer would like to talk to someone about their emotional well-being?	6 (25)
Not ranked	if the carer knows the wishes and preferences of the person they care for and they have been written down and shared (e.g. Advance Care Planning (ACP) document).	8 (31)

**Topic 1 - Caring situation, Topic 2 - Caring situation, Topic 3 - Relationship with health and social care professionals, Topic 4 - Respite and emergency care, Topic 5- Financial support and assessments, Topic 6 - Carer's health and well-being, Topic 7 - Support for the carer, Topic 8 - End of life and planning.*

7.12 Chapter summary

In this chapter, the findings from a two-round modified Delphi survey and a consultation exercise that was conducted with an expert panel were presented. The modified Delphi aimed to identify and prioritise items for inclusion in the CAT-S. The recruitment challenges encountered during the process and the strategies undertaken to resolve them were explained. Additionally, the procedures followed in selecting the final items for inclusion in the CAT-S have been described. In the next chapter the processes that were followed to pilot the feasibility of recruitment, usability and usefulness of the CAT-S and the findings from the CAT-S pilot are presented.

Chapter 8: CAT-S pilot (methods and findings)

8.1 Introduction

In this chapter, the findings are presented from a small pilot study that was conducted with stroke family caregivers and community-based stroke coordinators to explore their experiences when using the CAT-S. As presented in Chapter 4, this study comprised three main phases, namely the exploratory, implementation and evaluation phases, all preceded by a consultation exercise (pre-exploratory phase). Although the phases are presented separately in this thesis, in practice, there is an overlap between phases as described in Section 4.10 (Chapter 4). This pilot study was, therefore, conducted as part of both the implementation and evaluation phases and the findings are presented in three sections. Firstly, information from the CAT-S form provided jointly by the stroke coordinators and stroke family caregivers as part of the implementation phase is presented. This is followed by the findings from the staff feedback forms completed by the community-based stroke coordinators during the pilot, which however formed part of the evaluation phase. Lastly, the results from the semi-structured interviews conducted with stroke family caregivers four weeks after completing the CAT-S are reported. Methods are briefly described in this chapter to provide context for the findings. The pilot study was conducted for two months between October -December 2017.

8.2 Recruitment and data collection

As discussed in Chapter 3 and 5, the pilot of the CAT-S was conducted with stroke

family caregivers and community-based stroke coordinators to test the feasibility of recruitment, methods of data collection, its usability and usefulness in practice to identify stroke family caregivers needs for those supporting stroke survivors. The procedures described in Chapter 5 (Section 5.8.4) were followed to recruit participants to the study. Four community-based stroke coordinators completed the CAT-S with six stroke family caregivers (two coordinators completed the CAT-S with two stroke family caregivers each). At the back of the CAT-S, the community-based stroke coordinators documented the areas of need identified jointly with the stroke family caregivers and recorded any actions taken to address each of the identified alerts. Furthermore, they were requested to indicate who was responsible for the planned action and follow-up and also to indicate any review or follow-up dates. Approximately four weeks after completing the CAT-S, the research student conducted interviews with each of the stroke family caregivers. During the follow-up interviews, it was noted that one participant was not residing at the same address with the stroke survivor and did not meet the inclusion criteria and was therefore excluded, resulting in five participants. As discussed earlier in Chapter 5 (Methods) this was a small pilot with a small sample size.

8.3 Data analysis

Quantitative data collected from the CAT-S and the closed questions on the staff feedback form were analysed using simple descriptive statistics, such as frequencies and percentages. The information analysed included the number of alerts identified on the CAT-S, time taken to complete the CAT-S, action plans taken, whether the CAT-S was easy to complete and any missing items on the CAT-S. It is important to acknowledge that the sample is very small (n=5) therefore this may not provide much

useful information (Hunt and Lathlean, 2015). Another study incorporating a larger sample is therefore warranted. A content analysis approach was used to analyse the data collected from the semi-structured interviews with the stroke family caregivers. Three stages of content analysis advocated by Elo and Kyngas (2008) as described in Section 5.9.3 (Chapter 5) were followed. To aid rigour, a sample of the data was independently analysed by the supervisory team as described in Chapter 5 (5.10).

8.4 Results

8.4.1 Participants

Five stroke family caregivers participated in the pilot study and completed the CAT-S jointly with the community-based stroke coordinators. As illustrated in Table 35, the age of the participants ranged from 59 to 73 (mean age 67). All were female and spouses, except one who was an adult child (daughter) of the stroke survivor. The length of providing care varied ranging from six weeks to 15 years. Three family caregivers confirmed they had completed a carer's assessment, two were either unsure or had not had a carer's assessment completed. All were White British (categorised by the research student). The mean completion time of the CAT-S was 25 minutes.

Table 35: Demographic information of family caregivers (CAT-S pilot)

Participant number	Gender	Age	Relationship with stroke survivor	Time since caregiving	Carer's assessment	Number of CAT-S alerts
P1	Female	59	Daughter	6 months	No	0
P2	Female	60	Wife	6 weeks	Yes	1
P3	Female	71	Wife	15 years	Unsure	7
P4	Female	73	Wife	10 years	Yes	1
P5	Female	72	Wife	1 month	Yes	2

8.4.2 Identified needs of stroke family caregivers on the CAT-S

The first question on the CAT-S asked the stroke family caregivers if they had any needs or concerns in general. Three caregivers admitted to having needs or concerns about caregiving, whereas two denied having any needs. In total, eleven areas of need, resulting in eleven alerts, were identified from the completed five CAT-S forms. Seven of the alerts were classified as intermediate need alerts and four were classified as high need alerts jointly by the stroke family caregivers and the community-based stroke coordinators. As previously discussed in Chapter 5 (section 5.8.1), the alerts were subjectively scored by the family caregivers in agreement with the community-based stroke coordinators. The highest number of alerts were identified in relation to Question 2 (information - 3 alerts). A summary of the identified alerts is presented in Table 36.

Table 36: A summary of the identified family caregivers' needs on the CAT-S

Identified need	Intermediate risk alerts	High risk alerts	Total number of alerts
Q2. Do you need any information about the stroke your [x] has had and the expected recovery?	3	0	3
Q3. Do you require any training or support to provide care safely e.g. lifting and handling use equipment?	1	0	1
Q4. Do you need support to manage the behaviour of your [x]?	1	0	1
Q5. Do you have any specific plans in place in the event of an emergency?	0	0	0
Q6. Do you feel involved in decision-making and listened to by professionals about the care needed by [x]?	0	1	1
Q7. Do you need support to help manage your own emotions e.g. a listening ear or someone to talk to?	1	1	2
Q8. Do you need a break from caring during the day or overnight?	0	1	1
Q9. Do you have any other demands on your time in addition to your caring role? (e.g. working, young family, caring for grandchildren)	0	1	1
If appropriate include: Q10. Do you know your [x]'s wishes and preferences for EoL care? (if known, have they been written down and shared, e.g. advance care planning (ACP) doc?)	1	0	1
Total	7	4	11

8.4.3 Action plans

Various action plans were documented across the completed CAT-S. These included:

discussion and referral to the emotional support service, provision of information

regarding stroke, referral to the community pharmacist to obtain a dosette box to assist the stroke family caregiver with medication administration and a referral to the community stroke team for further equipment training.

In general, the action plan section was poorly completed by the community- based stroke coordinators compared to the other sections of the CAT-S. Variations were noted across the five completed CAT-S in terms of how the action plan section was completed. In most instances, the numbers of identified alerts appeared more than the stated actions documented on the CAT-S. One coordinator identified information about the disease (stroke) as a need but did not complete the action plan section. Similarly, the CAT-S that identified seven areas of needs only had three action plans completed. Upon further inquiries, after the pilot period, some coordinators cited increasing workload and time as reasons for the poor completion of the action plan section, as the coordinators were expected to complete the CAT-S in addition to their forms during the pilot period and thus prioritised their own paperwork over completing the CAT-S.

8.4.4 Feedback from the community-based stroke coordinators

As previously described in Chapter 5, the experiences of the community-based stroke coordinators when using CAT-S were collected via a staff feedback form (Appendix 24), which they completed immediately after conducting the CAT-S with the stroke family caregivers. One stroke coordinator completed the CAT-S on two occasions with two stroke family caregivers resulting in a total of five staff feedback forms being completed by the four stroke coordinators.

When asked about the instruction on the CAT-S, all but one community-based stroke coordinator reported that the instructions on the CAT-S were easy to follow and all were in agreement that the questions on the CAT-S read well. Furthermore, all respondents felt that the CAT-S could identify areas of risk for the stroke family caregivers. None of the respondents felt that there were any items missing on the CAT-S. All participants except one felt that the CAT-S could be completed electronically, while all respondents agreed that they could use the CAT-S with stroke family caregivers in the future. A summary of the responses to the closed questions on the staff feedback form is presented in Table 37.

Table 37: Responses to the closed questions on the staff feedback form

Questions	Yes (n)	No (n)
Q1. Did you find the CAT-S instructions easy to follow?	4	1
Q2. Did the questions read well (make sense)?	5	0
Q3. Were there any important questions missing from the CAT-S generally or in relation to this caregiver?	0	5
Q4. Did the questions lead to further appropriate discussion with the caregiver?	4	1
Q5. Did the questions identify any needs for this caregiver that would have remained undetected if the CAT-S had not been conducted?	3	2
Q6. Do you think the CAT-S could identify areas of risk for the caregiver or the care they provide to the stroke survivor?	5	0
Q7. Would you use the CAT-S with caregivers in the future?	5	0
Q8. Are there any particular groups of family caregivers that you would view as a priority to use the CAT-S with?	2	3
Q9. Do you think the CAT-S could be conducted electronically? (e.g. iPad or computer)	4	1

When asked about where to store the CAT-S, two storage options were suggested by the respondents and these were: a locked cabinet together with the patient's records and the CRM (an electronic patient information system that is utilised by the national stroke charity). When asked the most suitable personnel to complete the CAT-S with stroke family caregivers, the respondents cited therapists such as occupational therapist, psychologists and General Practitioners (GP) as well as volunteers from third sector organisations. For the question regarding the appropriate time to complete the CAT-S, various times were suggested as follows:

'Just before discharge from hospital' (P 4)
'Immediately after discharge' (P2)
'At any point as requested by the carer' (P 3)

8.6 Evaluation phase

8.6.1 Participants

The five stroke family caregivers who completed the CAT-S were interviewed as part of the CAT-S pilot. The demographic information of the participants is provided in Table 35.

8.6.2 Data collection

Five semi-structured interviews (four face-to-face and one telephone) were conducted in December 2017 with stroke family caregivers who completed the CAT-S with community-based stroke coordinators. All interviews were conducted at a venue chosen by the participants and lasted approximately 10 minutes.

8.6.3 Data analysis

The content analysis approach (Elo and Kyngas, 2008) was utilised to analyse the data as described in Chapter 5 (Section 5.9.3). Firstly, the interviews were transcribed verbatim and checked for accuracy. The next stage involved open coding and organising the data in categories extracting relevant information in relation to the questions on the interview guide. Each stage of the analysis was recorded to provide an audit trail. To enhance the rigour of data analysis and the findings, the involvement of more than one researcher to code the transcripts is recommended (Saks and Allsop, 2007; Silverman et al., 2017). Two out of five transcripts from this phase of the study were independently analysed by a member of the supervisory team to establish if they agreed with the accuracy of the interpretations made and enhance rigour as described in Chapter 5 (5.10).

In the next section, the findings from the interview data are presented under three main categories. To substantiate the findings, verbatim quotations will be used to illustrate the subcategories and the demographics to preserve the context of the individual record. To maintain confidentiality, the unique numbers that were assigned to participants during the interviews will be used instead of their real names. The participants will be labelled as follows: Participant number - relationship to stroke survivor e.g. wife and age (P1-Wife- 60).

8.6.4 Experiences of stroke family caregivers when completing the CAT-S

From the analysis of the interview data, three categories were identified. They include:

The CAT-S process, support received and their views regarding regular assessments.

CAT-S process

The participants were asked to comment on the length of time taken to complete the CAT-S with the community-based stroke coordinators. No criticisms were highlighted regarding the time taken to complete the CAT-S as all participants suggested that the length of time taken to complete the CAT-S was appropriate:

> '*It was fine she only took a few minutes, it didn't take too long to complete' P1-Daughter-59.*

Furthermore, the stroke family caregivers commented on the staff's approach when completing the CAT-S. All respondents felt that their needs were listened to by staff, and that staff were approachable. One participant highlighted that the explanations offered to her by staff were useful:

> *'She was welcoming and listened to me, she went through all the information and that was really helpful' P5-Wife-72.*

Overall, stroke family caregivers appeared to value completing the CAT-S with staff. Although one participant did not identify any alerts during the pilot, she expressed her views regarding the relevance of the CAT-S to other stroke family caregivers. For the other participants, completing the CAT-S was particularly useful as it enabled their needs to be identified and recorded by staff:

> *'We discussed the things that I needed help with… those questions have never been asked to me before, so I could answer them I know where I needed help you know and hopefully get all the help plus it's going on record, so everyone knows what you need' P3-Wife-71.*

Support received

The participants commented on the support that they had received following the completion of the CAT-S with the community stroke coordinators. All participants who had alerts identified during the CAT-S pilot stated that they received support regarding their identified alerts afterwards. The support received included: information about stroke, referral to emotional support, referral for a formal carer assessment and respite. One participant was referred to the community pharmacist and reported receiving a dosette box to assist her with administering medication to her husband:

> *'We were talking, and I mentioned the medications and [Staff name] offered to sort out the medications for my husband to have blister packs for my husband's medication… that has helped' P5-Wife-72.*

One participant highlighted how she had found the information that was given to her very helpful:

> *'I got information about it the services available… She gave me a booklet and some information about people having stroke and also the support services offered by [Organisation name] so that was very helpful…' P4-Wife-73.*

For another participant, completing the CAT-S triggered some questions regarding advance care planning and resulted in her requesting this information. She hoped that having such information would assist her in planning for the future with her husband:

> *'When I filled that form it triggered those kinds of questions… It does actually, it makes you think about things, it makes you think about what's going to happen after… you know and what kind of care if anything did happen so makes you think… so I know my husband doesn't need that now but it just makes you think and plan for the future, so I requested for some information' P3-Wife-71.*

Future use of the CAT-S

The views of the participants regarding the future use of the CAT-S were sought during the interview. All participants expressed positive views regarding regular assessment with the CAT-S. Although three participants did not specify the frequency of completing it with stroke family caregivers, two participants identified every three months as the appropriate frequency of completing the CAT-S with them:

> *'Well I would say that would be good… I would say every three months someone checking to see how you are, so they know what's going on… how I am coping' P3-Wife-71.*

Additionally, the participants were asked to identify staff who would be suitable to complete the CAT-S with stroke family caregivers on a regular basis. Although one participant did not specifically identify any staff group, four out of five participants identified staff from a national stroke charity as their preferred staff to complete the CAT-S with stroke family caregivers on a regular basis:

> *'I think this was very good, she would help you in any way at all… so the [national stroke charity staff] would be appropriate' P1-Wife-59.*

8.7 Chapter summary

In this chapter, the findings from the CAT-S pilot conducted as part of the implementation phase and evaluation phase were presented. As discussed earlier, in reality the action research process is cyclical with overlapping phases, therefore, although the staff feedback forms were completed during the implementation phase, they formed part of the evaluation phase. The findings from the CAT-S pilot suggest that it is an important screening tool which is valued by both staff and stroke family

caregivers. During the pilot various alerts (needs of stroke family caregivers) were identified, which resulted in stroke family caregivers receiving timely support. In the next chapter, a discussion of this study's findings will be presented in relation to existing published literature.

Chapter 9: Discussion

9.1 Introduction

This chapter provides a discussion of the study's main findings in relation to the existing published literature. The literature identified in the background chapter (Chapter 1) and the literature review chapters (2 and 3) will be drawn upon. As presented in Chapter 3, this study aimed to answer the following research question: 'How can the views and experiences of stroke family caregivers and staff working within stroke services be incorporated to adapt the CAT and develop the CAT-S?' The study aim has been achieved. The CAT-S was developed sequentially across three phases utilising multiple methods with stroke family caregivers and a wide range of staff working within diverse stroke services. The findings from each phase are presented in Chapters 6, 7 and 8. In this chapter, the findings from the three phases are synthesised to describe the relevance of the CAT-S to clinical practice and further highlight similarities and differences between the CAT-S and existing assessment tools. Prior to this, a brief discussion of the two themes identified from the semi-structured interviews in the exploratory phase are provided. The interviews in conjunction with the literature review, as discussed in Chapter 2, were undertaken with the specific aim of informing the contents of the CAT-S (Streiner, Norman and Cairney, 2015).

9.2 Challenges experienced by family caregivers of stroke survivors

As discussed in Chapter 5, semi-structured interviews were conducted in the first part of the exploratory phase to explore the experiences of stroke family caregivers and identify their main challenges when providing care. Two main themes were identified from the analysis of the interview data, namely the effects of caregiving and the unmet needs of the caregivers.

Effects of caregiving

Providing care to individuals following stroke can contribute to various negative effects upon their family caregivers' physical health, emotional well-being, social situations, and financial status. Consistent with existing literature (Backstrom and Sundin, 2009; Simeone et al., 2016; Wagachchige, Samarasinghe and Elgan, 2018), the family caregivers in this study reported tiredness and physical strain, affecting their physical health. Furthermore, there was an overwhelming report from family caregivers of the effects of caregiving on their emotional well-being. Frustration and depression were highlighted by the participants and this appeared to stem from the sudden changes to their lifestyle, lack of support from health and social care professionals, giving up employment to provide care and struggling to manage the changed behaviour of the stroke survivor. Similarly, as discussed in Chapter 2, the effects of caregiving on the emotional well-being of stroke family caregivers have been widely reported in the literature (Haley et al., 2009; Danzyl et al., 2013; Gholamzadeh et al., 2015; Masuku, Mophosho and Tshabalala, 2018). Therefore, it can be proposed that since the effects

of caregiving identified in the current study are similar to the findings in other studies, the CAT-S can potentially be relevant to family caregivers supporting stroke survivors in other locations in the UK and abroad.

Unmet needs

Another recurrent theme that was identified from the interviews relates to the unmet needs of the family caregivers. The unmet needs were varied but expressed as support needs that the family caregivers desired to have but did not receive. Due to the physical and emotional exhaustion of providing care, family caregivers identified respite care as an important support need. This finding is consistent with the concerns expressed by stroke family caregivers in other studies (Bulley et al., 2010; Cameron et al., 2013; Torregosa, Sada and Perez, 2018). Furthermore, the family caregivers identified the lack of information from health and social care professionals. The information needs highlighted by the family caregivers concerned local support services, the expected recovery of the stroke survivor, and information regarding medication. The lack of information among stroke family caregivers is, similarly, a common finding in the literature (Greenwood et al., 2009a; Simeone et al., 2016; Lopez-Espuela et al., 2018). For most of the family caregivers in this study, the absence of this support appeared to be stressful, whilst for others, this resulted in exhaustion as they attempted to source the required information and support. It can therefore be argued that the CAT-S provides an opportunity for the unmet needs of stroke family caregivers to be identified, discussed and addressed with health and social care professionals and staff from third sector organisations.

9.3 Assessing the needs of the family caregivers of stroke survivors

Carer's assessment

An important finding across the three phases of this study as presented in Chapters 6, 7 and 8, was the low number of family caregivers who had their needs assessed through statutory carer assessment processes. Only four out of sixteen family caregivers in the exploratory phase (part one) had completed a carer assessment. Likewise, in phase two, less than half of the family caregivers who took part in both rounds of the modified Delphi survey reported having had their needs assessed in this way. Similar patterns were observed during the pilot of the CAT-S as presented in Chapter 7. The Carers (England) Act (2014) places a duty on local authorities to assess any family caregiver who requests an assessment or who appears to need support (Great Britain Parliament, 2014). Furthermore, national stroke guidelines recommend that following a stroke, family caregivers should be offered an assessment of their needs separate from the stroke survivor (NICE, 2008; ISWP, 2016). Findings from the current study suggest that the needs of stroke family caregivers are not routinely assessed in clinical practice. The lack of such carer assessment has been previously highlighted as a concern by the Care Quality Commission (CQC) who reported that, nationally, less than half of family caregivers were offered an assessment and received support (CQC, 2011). Nevertheless, it appears that the problem with carer assessment is prevalent among the general family caregiver population. In a national survey with approximately 7,000 respondents, 20% of the family caregivers did not receive an assessment of their needs (Carers UK, 2018).

In addition, delays in assessing the needs of family caregivers were observed in the current study. For example, one family caregiver (P2), as illustrated in Table 17, was still waiting to have a carer's assessment despite providing care for seven months. Such delays can potentially expose family caregivers to adverse effects on their overall health and well-being (Greenwood et al., 2009a). This study's findings therefore suggest that as a result of these delays, opportunities to provide support to stroke family caregivers are being missed.

To enable stroke family caregivers to continue with their role and to also ensure that they live fulfilled lives besides caregiving, it is important that their needs are identified and addressed by health and social care professionals (Van Heughten et al., 2006, Coombs, 2007; ISWP, 2016). Reductions in social care expenditure and widespread pressures on health and social care services in the UK have nevertheless resulted in family caregivers not always receiving sufficient support (Carers UK, 2016). Given these financial constraints, it is unlikely that the reliance on existing approaches to assessment will be a realistic option to having the needs of stroke family caregivers assessed and addressed. Thus, this study's findings illuminate the need for a proactive approach in identifying the needs of stroke family caregivers.

The use of an evidence-based triage tool such as the CAT-S, which was developed as part of this study, offers opportunities for the needs of the family caregivers of stroke survivors to be identified and addressed and for a detailed assessment to be undertaken if required (Knighting et al., 2015, 2016). The presence of the traffic light system on the CAT-S can enable health and social care staff as well as volunteers

from third sector organisations to assist stroke family caregivers in prioritising their needs by indicating the level of their needs (low, intermediate or high). This will provide opportunities for individuals completing the CAT-S to focus on resolving the most important problems before reaching a crisis point. Furthermore, as established from the pilot of the CAT-S (Chapter 8), it is an easy-to-use tool that can be utilised by non-clinical staff from third sector organisations such as community-based stroke coordinators. Lack of time, lengthy forms and the need for professionals such as social workers to complete assessments have been previously reported as barriers to their completion (Gilles et al., 2000; Scourfield, 2005; Greenwood et al., 2011). Therefore, the use of the CAT-S by non-clinical staff could render the assessment of stroke family caregivers' needs more accessible, cheaper and structured. Since the CAT-S offers suggestions for further action, this can trigger appropriate referrals being made and result in family caregivers receiving timely support.

Another finding was regarding the lack of knowledge about carer assessments among the family caregivers. As noted previously, during the interviews, some family caregivers demonstrated ignorance about carer assessments and what they entailed, whilst others appeared to confuse the social services carer assessment with assessments for financial benefits such as attendance allowance. A similar finding was observed in the modified Delphi survey where some family caregivers were uncertain regarding having completed a carer assessment, as illustrated in Tables 21 and 25 (Chapter 7). The findings echo those from a commissioned report, which concluded that further work is warranted to ensure that family caregivers are aware of their rights and that the quality of assessment is of a high standard (Bennett, 2016). The low

uptake of carer assessment among family caregivers can be partly explained by their lack of information regarding carer assessments. Thus, it could be proposed that the inclusion of the question regarding carer assessment on the CAT-S provides an opportunity for staff, or volunteers, completing the CAT-S with stroke family caregivers to provide them with this information and signpost them for further support if required.

Views regarding the frequency and preferred individuals to complete assessments

It is clear from the current study that both staff and family caregivers who support stroke survivors' value regular assessments. During the exploratory phase (part one), family caregivers reported some of their perceived benefits to having regular assessments such as having a sense that they are not forgotten, validating their role and enabling them to evaluate their priorities. Furthermore, the respondents of the modified Delphi survey (both staff and family caregiver cohorts) identified the period of three to six months as their preferred frequency for reassessment. The preference for having regular assessment is particularly important with this population as the needs of stroke family caregivers may change over time (Cameron et al., 2013). For instance, during the initial post-stroke period, family caregivers tend to focus on the survival of the individual who has suffered a stroke whilst later on, the focus shifts to the long-term effects of stroke on the survivor (Brereton and Nolan, 2000; Smith et al., 2004; King and Semik, 2006; Perry and Middleton, 2011). However, what appears to be missing in practice is a short screening tool such as the CAT-S that identifies stroke family caregivers at risk, leading to an opportunity for a formal assessment.

In addition, as discussed in Chapter 1, most strokes occur in people over the age of

65 (NAO, 2010; ISWP, 2016). As highlighted in the literature, it is most likely that the family caregivers of these stroke survivors will be their spouses who are in their sixth decade of life, with multiple comorbidities themselves (Greenwood et al., 2009a, Mackenzie and Greenwood, 2012). Similar observations were made in this study. For example, due to advancing age, the majority of family caregivers described changes regarding their own physical abilities to continue providing support to the stroke survivor. Similar findings have been reported in other stroke studies in the UK (Smith et al., 2004; Katbamna et al., 2017). Additionally, Greenwood et al. (2009b) highlighted that the needs of family caregivers might change as the stroke survivor's abilities improve. A typical example is when the stroke survivor regains their ability to mobilise, they may be at risk of falling thereby increasing the demands placed on the caregivers in relation to supervision.

The findings from the current study therefore emphasise the importance of assessing the needs of stroke family caregivers throughout the caregiving trajectory as there is evidence, both from this study and the wider literature that their needs are bound to change. Furthermore, current UK stroke guidelines (IWSP, 2016) and international stroke guidelines (Lindsay et al., 2014; Stroke Foundation Australia (SFA), 2017) recommend that the needs of the family caregivers are reassessed whenever there is a significant change in circumstances such as declining health of the family caregiver or of the individual who has suffered a stroke. However, as previously discussed, there are delays in getting an assessment. Furthermore, there is currently a lack of screening tools for use with stroke family caregivers as identified in Chapter 2, and thus, the CAT-S was developed to fill this gap. The use of a screening tool can assist

in identifying and prioritising family caregivers with the greatest level of needs to undergo a comprehensive assessment (Knighting et al., 2015, 2016), thereby enabling recommendations in the stroke guidelines to be achieved.

It was apparent from the Delphi survey that staff and family caregivers have their own views regarding the preferred individuals to complete the CAT-S, with differences and commonalities observed. In both rounds of the survey, family caregivers identified their General Practitioner (GP) whilst staff selected social workers amongst their top preferred groups. The different views between staff and family caregivers are important and require further exploration in future research. However, contrary to these findings, another study conducted with stroke family caregivers in the UK, (Greenwood et al., 2011) reported that stroke family caregivers' expectations of support from their GP, for themselves, are low. They further indicated that family caregivers regarded GPs as the main source of support for the stroke survivor rather than themselves. The choice of GPs over social workers by family caregivers in the current study may imply that family caregivers prefer to have their needs assessed by staff with whom they have a relationship and regular contact.

Furthermore, the negative portrayal of social workers by the media both nationally and internationally may provide an explanation as to why social workers were not highly rated by the family caregivers in this study (Booker, 2009; Beddoe, 2015). Additionally, it appears that family caregivers favour staff from third sector organisations to complete their assessments. In the current study, staff from a national stroke charity were consistently highly rated in the modified Delphi survey. The finding mirrors those

from a study conducted in the UK with stroke family caregivers (Cecil et al., 2011) where the services offered by a third sector organisation were generally favourably mentioned and community-based workers were considered helpful. Conversely, the support offered by social workers was not considered as appropriate or helpful. As evidenced from the findings of the pilot (Chapter 8), the CAT-S can be easily used by staff from third sector organisations such as the community-based stroke coordinators. Further research with a larger number of volunteers and staff from third sector organisations that support stroke family caregivers is required to establish their views and also determine if this approach can increase the number of family caregivers who have their needs assessed.

It is interesting to note that the staff panel, which predominantly consisted of therapists as presented in Chapter 7, highly rated community therapists as their preferred staff group to complete the CAT-S with stroke family caregivers. This finding may therefore indicate that therapists view assessing and supporting the needs of stroke family caregivers as a vital part of their role and could potentially be a human resource to target. However, research specifically exploring the experiences and expectations of stroke family caregivers and community therapists in supporting the needs of stroke family caregivers in the UK is sparse. Further research on this topic is therefore warranted.

9.4 Prioritised topics and items included in the CAT-S

As highlighted in Chapter 7 (Tables 29 and 34), two topics and 12 items were

prioritised to be included in the CAT-S. The two highly ranked topics in the current study relate to understanding the current caring situation and the carer's health and wellbeing. This highlights the views of family caregivers and staff about the importance of the two topics when providing support to family caregivers who support stroke survivors. The findings concur with those from the original CAT (Knighting et al., 2015, 2016) and other caregiver populations (Ewing et al., 2013). Furthermore, the two domains are consistent with Twigg's conceptualisation of the relationships that exist between family caregivers generally and social care agencies as co-workers and co-clients (Twigg, 1989). Within the former relationship (family caregivers as co-workers) the family caregivers' needs are addressed so that they can continue with their caregiving role. In the latter relationship (family caregivers as co-clients), the family caregivers' needs and well-being are the main focus of support (Twigg, 1989; Twigg and Atkins, 1995).

National stroke guidelines in the UK (ISWP, 2016) recognise that family caregivers have their own needs. They further identify family caregivers as partners in the provision of care to the stroke survivor and recommend that they are supported in this role (ISWP, 2012, 2016). Findings from the current study therefore complement these assertions, highlighting that when assessing the needs of stroke family caregivers, the focus must include their needs as co-workers as well as their needs as a co-client. The findings further support existing literature where some authors propose that the rehabilitation process of stroke survivors can be improved by considering the position of their spouses as caregivers (equal partners in the care process) and as clients (having their own needs, rights and aspirations) (Visser-Meiley et al., 2006). Since

these two topics are included on the CAT-S, it can be argued that utilising it with the family caregivers of stroke survivors will facilitate the recommendations made by the national stroke guidelines to be achieved and ensure that stroke family caregivers are supported in their caregiving role.

It is important to note that the end-of-life topic was ranked as the least important topic by both panels (staff and family caregivers) in the modified Delphi survey. This finding suggests that when supporting the family caregivers of stroke survivors, both staff and family caregivers focus on the present rather than the future. The finding is supported by existing literature which suggests that stroke family caregivers concentrate on the present rather than the future as a coping strategy for uncertainty by adapting routines (Danzyl et al., 2013; Katbamna et al., 2017) and 'taking things slowly' (Greenwood et al., 2009b: 177). Similar comments were noted in the first part of the exploratory phase of the current study where one family caregiver (P5) reported 'living for the day' as her coping strategy. The timing of discussing end of life issues with stroke survivors and their family caregivers is therefore important as the focus may be on recovery and not end of life during the early stages post stroke. These notions may offer explanations why the end-of-life topic was the least ranked topic by both panels in the current study. Moreover, evidence from other studies suggests that there is reluctance among health and social care professionals to initiate end-of-life discussions with their patients due to fear and lack of knowledge (Hamric and Blackwell, 2007; Barclay et al., 2011; Davis, 2015). This may be another reason why the end-of-life topic was ranked as the least important topic in this study. The next section will discuss the 12 items as presented in Table 34 that were prioritised and included in the CAT-S under the two topics

(current caring situation and carers health and well-being).

9.4.1 Current caring situation

Stroke survivors' difficult behaviours

It is obvious from this study's findings that managing the behavioural problems of stroke survivors is particularly challenging for their family caregivers. Although not all individuals will exhibit difficult behaviours following a stroke, high prevalence rates of cognitive impairment of between 20 to 80 percent have been reported in the literature, which may impact on the stroke survivors' mood and behaviour (Knapp, 2010, Sun, Tan and Yu, 2014). Nonetheless, literature suggest that the physical needs of stroke survivors attract more attention in clinical practice compared to their behavioural problem. Family caregivers in a study by Smith et al. (2004: 241) referred to the cognitive problems of stroke survivors as an *'invisible disability'* for which health and social care professionals failed to provide support. Likewise, family caregivers in the first part of the exploratory phase of this study, reported inadequate support from professionals to manage the stroke survivors' difficult behaviours. The most challenging behaviours for the family caregivers included mood swings, depressed mood, lack of motivation and in some instances verbal abuse. Similar behaviours have been reported in other studies (Bakas et al., 2002; Smith et al., 2004; Bulley et al., 2010).

Given that the item regarding the stroke survivor's behaviour was highly rated and included in the CAT-S indicates that this is an important area where stroke family caregivers require support. This finding is consistent with the literature where

managing the behavioural problems of the stroke survivor was identified as the most difficult task (Bakas et al., 2004; Mackenzie et al., 2007; Danzyl et al., 2013) and further supported by the interview data from the exploratory phase (part one) of this study. In addition, literature suggests that family caregivers can easily adapt to the physical aspects of caregiving compared to managing the behaviour exhibited by the stroke survivor (Smith et al., 2004; Grant et al., 2006; Bulley et al., 2010). Similar observations were noted in this study as family caregivers described having developed routines or sought help from family members or even paid caregivers to cope with the physical aspect of caregiving. However, managing the behaviour of the stroke survivor was reported as the hardest and an ongoing issue for most family caregivers. Moreover, other authors have argued that whilst the physical deficits of stroke may be apparent in the hospital environment, behaviour deficits may not be fully realised until after hospital discharge (Smith et al., 2004; Clarke et al., 2013).

It can therefore be argued that the inclusion of the item regarding the difficult behaviours of the stroke survivors on the CAT-S can assist in bringing this potentially 'invisible topic' to the fore. This is important particularly with issues related to safeguarding. For example, literature suggests that family caregivers who support individuals with difficult behaviours are at an increased risk of experiencing abuse from the individual they care for or may intentionally or unintentionally abuse the individual who they support as a coping strategy (Isham, Hewison and Bradbury-Jones, 2017). Furthermore, there is evidence highlighting that many practitioners lack the confidence to discuss violence and abuse with service users and their family caregivers (Tower, 2006; Bradbury-Jones, 2015). The CAT-S may thus assist in raising the profile of these

safeguarding issues and provide opportunities for protecting both the stroke survivor and their family caregivers from potential abuse and harm.

It is important to note that out of the five stroke-specific tools identified in Chapter 3, only the Stroke Caregiver Unmet Resource Needs Scale (URNS) (King et al., 2013) and the Caregiver Burden Scale (CBS), (Elmstahl, Malmberg and Annerstedt., 1996) contain items regarding the stroke survivor's behaviour. Nonetheless, it can be argued that the questions present on the two tools may be more relevant to the research settings and not clinical practice and are therefore unlikely to result in the appropriate support being given to stroke family caregivers. In contrast to the URNS and the CBS, the item on the CAT-S (Question 4: Do you need support to manage the behaviour of your x) is more likely to result in appropriate support being given to stroke family caregivers. Bakas et al. (2004) have suggested that assisting family caregivers to recognise that many of these behaviours are stroke-related can provide a first step in dealing with difficulties related to providing care. Nonetheless, as revealed in this study providing information alone about the causes of the stroke survivors' behaviour may not be sufficient for the family caregivers. One participant (P7), in the exploratory phase (part one) of this study was pre-warned by the stroke team about her husband's behaviour, however, she reported inadequate support from health and social care professionals. Strategies on how to manage these challenging behaviours would have perhaps been more useful to this stroke family caregiver.

<u>Understanding the expected recovery of the stroke survivor</u>

Findings from the current study suggest that, following a stroke, it is important for

family caregivers to understand the expected recovery of the stroke survivor. In addition to this item being highly rated in the modified Delphi survey, the family caregivers in part one of the exploratory phase, reported uncertainties regarding the expected recovery and long-term disability of the stroke survivor. Consequently, this uncertainty affected the family caregivers' ability to plan for the future, leading to frustration and stress for most family caregivers. Similar findings have been reported in other studies with stroke family caregivers (Coomb et al., 2007; Greenwood et al., 2009b; Katbamna et al., 2017).

The current UK stroke guidelines (ISWP, 2016) advise that the family caregivers of individuals following stroke should be offered educational programmes which explain the nature, consequences and prognosis of stroke. However, in clinical practice, the distinctive characteristics of stroke such as the diversity of effects on individuals and the relatively unpredictable nature of recovery creates challenges for clinicians. Family caregivers in the first part of the exploratory phase of this study reflected upon the ambiguous responses that they had received from the stroke team regarding the stroke survivor's expected recovery. This finding supports the literature where the lack of explicit communication regarding the expected long-term disability of the stroke survivor was highlighted by family caregivers (King and Semik, 2006; Greenwood et al., 2009b; O'Sullivan et al., 2009).

Contrary to the CAT-S, none of the stroke-specific tools presented in Chapter 3 contain an item specifically addressing the concerns of stroke family caregivers regarding the expected recovery of the stroke survivor. However, the Carers Assessment Scale

(Mackenzie, Holroyd and Lui, 1998) contains a question regarding the 'lack of information about patient diagnosis', which may or may not trigger similar conversations between health and social care professionals and the stroke family caregivers. Nonetheless, this study's finding, and existing literature suggest that uncertainties regarding the expected recovery of the stroke survivor is an important area for family caregivers that needs to be addressed. Greenwood et al. (2009b) propose that uncertainty regarding both short- and long-term issues is a prominent concern for stroke family caregivers which has received less attention from health and social care professionals. They further add that open and honest discussions with clinicians enable family caregivers to cope and deal with uncertainty (Greenwood et al., 2009b). The inclusion of this item on the CAT-S will potentially facilitate conversations between stroke family caregivers and health care professionals on this subject. Furthermore, it will enable family caregivers who have concerns in this area to be referred to appropriate services for support.

Family caregivers coping strategies

As illustrated in Chapter 7 (Table 34), an item regarding the ability of the family caregiver to cope with the various aspects of caregiving was prioritised (ranked fourth) and included in the CAT-S. It is important to note that in comparison to the CAT-S, none of the stroke-specific tools discussed in Chapter 3, contain an item regarding coping in general. Although the Bakas Caregiving Outcomes Scale (BCOS) (Bakas and Champion, 1999) contains an item regarding coping, this is targeted towards coping with stress, which may arguably have a different focus.

Following a stroke, both survivors and their family caregivers have to cope with lasting changes and consequences (Rochette et al., 2007; Visser-Miely et al., 2009; McGurk, Kneebone and Pit ten, 2011). Evidence from the literature proposes that the use of problem-focused coping strategies and acceptance is more beneficial for adjustment than the use of avoidant styles of coping and emotion-focused strategies (other than acceptance) are associated with poorer outcomes such as depression for the family caregiver (Chumbler et al., 2004; Visser-Miely et al., 2005; Rochette et al., 2007). In the exploratory phase (first part) of this study, stroke family caregivers described utilising both active and passive coping strategies, which varied depending on their personal circumstances and resources, in order to mitigate the effects of caregiving. They referred to 'acceptance' (P1), 'their religious beliefs' (P5), 'resilience due to childhood hardships' (P3) and 'feeling lucky to have the stroke survivor alive' (P10). Similar coping strategies have been reported by family caregivers in other stroke studies (Greenwood et al., 2009a; Danzyl et al., 2013; Van Dongen, Josephsson and Ekstam, 2014; Katbamna et al., 2017).

Understanding the different coping strategies and how family caregivers deal with the challenges that they experience is vital in identifying how to best support family caregivers and enhance their resilience (Visser-Miely et al., 2009). Evidence from the stroke literature further highlights that the degree of the stressor has a lesser effect on family caregivers' longer-term psychosocial functioning compared to how they cope with it (McGurk, Kneebone and Pit ten, 2011). Consequently, some authors propose that the assessment of family caregivers' coping strategies and psychosocial interventions, if applicable, should therefore be a routine part of stroke care (Visser-

Miely et al., 2009; McGurk and Kneebone; 2013). Findings from the current study suggests that this is yet to be achieved as none of the family caregivers in the first part of the exploratory phase of this study indicated having discussed coping strategies at any point following the stroke.

Additionally, Lazarus and Folkman (1984) highlighted that in order to achieve success, coping strategies should be studied in relation to specific stressors as people use different strategies for different problems. Given that the item regarding coping was prioritised in this study, it was presented as an open- ended question (Question 1) on the CAT-S, drawing upon the initial CAT (Knighting et al., 2015, 2016) and also feedback received from the VAG. The inclusion of this item as an open-ended question on the CAT-S will allow stroke family caregivers to explore their specific stressors, including those not included on the CAT-S and enable health and social care professionals to offer targeted support and interventions.

The training needs of family caregivers following stroke

Identifying the training needs of the family caregivers of stroke survivors appears to be an important area to consider when supporting them as suggested by this study's findings. The sudden nature of a stroke means that family caregivers usually have minimal time to adapt and learn new skills required to assist the stroke survivors with activities such as toileting, bathing and feeding (Greenwood et al., 2009a; ISWP, 2016) while maintaining their own health and well-being. Previous research has reported that due to lack of training and appropriate skills to provide the physical aspects of care, most stroke family caregivers feel incompetent to support the stroke survivor (Brereton

and Nolan, 2000; Smith et al., 2004; Gholamzadeh et al., 2015; Katbamna et al., 2017). This subsequently results in stress and exhaustion as stroke family caregivers gain the necessary skills required to provide care through trial and error.

In contrast, there was little mention regarding skills training to provide the physical aspects of care from stroke family caregivers in the exploratory phase (part one) of this study. A possible explanation is that in comparison to the above studies, most family caregivers in this study had been providing care for over a year. There is a possibility that during this time, stroke family caregivers could have developed some routines and strategies to cope with the physical aspects of caregiving. Furthermore, most family caregivers in the current study reported that over time, the physical abilities of the stroke survivor improved, and caring became 'much easier' (P7). The exception were the four stroke survivors whose physical abilities had worsened following a recurrent stroke, a finding which is reflected in the wider literature (Buschenfield, Morris and Lockwood, 2009; Danzyl et al., 2013).

Additionally, another view could be that stroke family caregivers in the current study had prior caregiving experience. Five family caregivers in the exploratory phase reported that they were able to cope with the physical aspects of caring due to prior experience gained from previous employment in nursing and residential homes. Similar findings were reported by Greenwood et al. (2009b) in the UK, where stroke family caregivers who had prior caregiving experience (established family caregivers) required less training to perform the physical aspects of care compared to new family caregivers. This finding highlights that stroke family caregivers will have varying needs depending on their previous experiences and situations. It is therefore important for

health and social care professionals to tailor training needs to individual situations.

Nonetheless, as illustrated in Table 34, the item regarding the training needs of family caregivers to provide physical care was prioritised in the second part of the exploratory phase to be included in the CAT-S. This finding is supported by national stroke guidelines which recommend that professionals should provide stroke survivors and their family caregivers with information and skills training early, starting with the acute hospitalisation phase (ISWP, 2012, 2016). Furthermore, although evidence is sparse among the stroke population, a randomised controlled trial conducted in the UK indicated some benefits for both the family caregivers and stroke survivors (Karla et al., 2004). A training programme that included basic nursing and manual handling techniques, significantly reduced family caregivers' symptoms of depression, anxiety and caregiver burden and assisted stroke survivors to achieve a greater independence at an early stage (Karla et al., 2004). Furthermore, another recent randomised controlled trial conducted with stroke family caregivers in Iran, noted a significantly decreased frequency of pressure ulcer incidence in stroke survivors whose family caregivers had received home-based care training when compared to the stroke survivors in the control group who had received routine care (Karimi et al., 2018). Similar outcomes have been reported in other family caregiver populations. In a mixed-methods study conducted with the family caregivers of people with cancer, providing home- based care at the end of life, a booklet intervention was developed to support family caregivers with their caring skills. This resulted in them feeling more positive about caregiving, more re-assured and competent in their role (Luker et al., 2015).

Currently, to improve preparation for the caregiving role, most stroke units and acute stroke services incorporate skills training for family caregivers as part of rehabilitation whilst the stroke survivor is still hospitalised. However, some authors argue that fewer opportunities may be available to practice these important caregiving skills adequately particularly in settings with short inpatient stays (Clarke et al., 2013). Furthermore, household environments may also differ from rehabilitation settings making it difficult to transfer these skills to home settings (Kerr and Smith, 2001; Grant, 2014). An integrated intervention approach to skills training whereby the initial hospital training is supported by follow-up training after discharge delivered by community teams is thus recommended (Forster et al., 2013). The inclusion of the item regarding training needs on the CAT-S will provide an opportunity for stroke family caregivers to explore their needs in this area and be signposted to appropriate services if any training needs are identified. Additionally, using the CAT-S with stroke family caregivers will ensure that their training needs are re-assessed following any changes in circumstances over time. In view of the reductions of the length of stay on stroke units in recent times (IWSP, 2016), ensuring that family caregivers receive the right follow-up support to provide care safely will remain an important area for stroke family caregivers.

Among the stroke-specific tools presented in Chapter 3, only the Carer Assessment Scale (CAS) (Mackenzie, Holroyd and Lui, 1998) contains two separate questions relating to dealing with the physical aspects of caregiving such as dealing with personal care, toileting and incontinence. In contrast, the CAT-S contains one question regarding the training needs of stroke family caregivers since it is designed as a screening tool where the specific training needs of the family caregivers can be

explored individually with staff or volunteers when completing the CAT-S. Furthermore, unique to the CAT-S are the accompanying suggestions for further action that will enable timely support referrals and support to be offered to stroke family caregivers.

Contingency plans during an emergency

Having contingency plans in place for emergency situations appears to be an important area of concern for the family caregivers of stroke survivors as revealed from this study's findings. During the first part of the exploratory phase, the family caregivers reported worrying about what would happen on occasions where they became unavailable to provide care due to illness or other emergencies. This finding is consistent with the results from other stroke studies (O'Connell, Baker and Prosser, 2003; Cecil et al., 2011). In addition, the family caregivers in the current study highlighted some concerns regarding their advancing age, declining health and their ability to continue with the provision of care in the longer term. Similar concerns have been reported in the literature, particularly amongst older stroke family caregivers (Chow and Tiwari, 2014; Simeone et al., 2016; Katbamna et al., 2017). It is therefore unsurprising that family caregivers in this study expressed these concerns since the majority were over the age of 66 (Chapter 6, Table 18).

Despite their concerns, it appears that family caregivers in the current study did not have any contingency plans in place for an emergency, with some assuming that family members 'would step in' (P5). The absence of contingency plans in this study is consistent with a study by O'Sullivan et al. (2012) who reported that stroke family

caregivers did not have a contingency plan in place at one, three and six months post hospital discharge. Research specifically focussing on contingency planning among stroke family caregivers is sparse. The findings from the current study thus contribute to this literature suggesting that even in the longer term, most family caregivers do not have contingency plans in place for an emergency despite this being an area of concern for family caregivers.

A national charity organisation that supports family caregivers in the UK (Carers UK) advises them to create an emergency plan for themselves and the individual that they care for (Carers UK, 2018). They further add that every family caregiver who has an assessment should be asked about emergencies and offered help to plan for them. However, as established from this study and wider literature, having a contingency plan for emergencies does not appear to be a common practice among stroke family caregivers. Furthermore, it is unlikely that stroke family caregivers will receive support regarding emergency planning via a carer assessment, as the findings from the current study and wider literature suggest low uptake of carer assessments among family caregivers generally. Having a plan in place can assist in easing the worries expressed by family caregivers if they are not able to provide care at any point in the future (Carers UK, 2018). The CAT-S therefore offers opportunities for discussions regarding emergency planning to be held and the plans to be created.

The importance of considering anticipated social support when designing interventions for family caregivers and stroke survivors has been highlighted in the literature. Some authors have suggested that it would be beneficial for the interventions to address

family caregivers' concerns regarding where they would access more support in the future if needed (McGurk et al., 2011). Additionally, other researchers have concluded that interventions are required to assist stroke survivors and family caregivers with preparedness planning (O'Sullivan et al., 2012). Unlike the CAT-S, none of the assessment tools presented in Chapter 3 contain items or questions regarding emergency planning. It can therefore be argued that the CAT-S developed in this study may fill this gap. Furthermore, the inclusion of the item regarding emergency planning can assist staff and volunteers to share emergency contacts with family caregivers such as out-of-hours services, which may not always be known by the family caregivers.

9.4.2 Carer's health and well-being

As discussed in Section 9.4 of this chapter, the other topic that was highly ranked in this study relates to the family caregivers' health and well-being. The following section will discuss the items that were included in the CAT-S under this topic.

Family caregivers' demands on their time in addition to their caring role

Overall, the highest ranked item in this study was regarding the family caregivers' demands on their time in addition to their caregiving role (Table 34, Chapter 7). Generally, most family caregivers have other demands on their time such as employment, other caregiving responsibilities (supporting children, grandchildren, spouses, parents) and education (Office of National Statistics (ONS), 2011; Carers UK, 2018). Similar observations were made in this study as most family caregivers who participated across all the phases of this study reported additional demands on

their time.

It was apparent in the current study that stroke family caregivers who have competing demands on their time experience additional challenges. For instance, in part one of the exploratory phase, family caregivers who had other caregiving responsibilities or employment, in addition to supporting the stroke survivor, reported heightened levels of physical and mental exhaustion. This finding is supported by existing literature where stroke family caregivers, who were combining employment and providing care, reported challenges in balancing the demands of both roles (Bastawrous et al., 2015; Simeone et al., 2016; Katbamna et al., 2017). Evidence from studies in other populations has similarly reported poorer outcomes for family caregivers with additional demands on their time including depression and social isolation (Abramson, 2015). Furthermore, Abramson (2015) has argued that it is imperative for health professionals to begin to assess and provide support to assist family caregivers with competing demands on their time. It can therefore be suggested that the CAT-S, can enable the exploration of demands on family caregivers' time.

Additionally, as discussed in Chapter 1 (Section 1.5.2), evidence from the literature suggests an increasing number of older family caregivers in recent years (Carers UK, 2015). This group of older family caregivers have been referred to as 'panini carers', who are typically older adults who find themselves sandwiched between their own age-related changes and needs and also providing care to their adult child, spouse, siblings or grandchildren (Abramson, 2015: 253). Family caregivers who participated in all three phases of this study were mostly aged over 66. Ageing family caregivers must

cope with their own health problems, which consequently pose additional risk on their health and well-being. This can lead to significant levels of stress as they face their own ageing and approaching mortality (Abramson, 2015). It can therefore be argued that focussing on the needs of ageing family caregivers within stroke services will increasingly become a priority due to longer life expectancies, and the fact that most strokes occur in individuals over the age of 65 (NAO, 2010; ISWP, 2016). Thus, the CAT-S offers opportunities for the needs of this group of older family caregivers to be identified and addressed. In comparison to the CAT-S, none of the existing tools discussed in Chapter 3, contain an item regarding the needs of stroke family caregivers who have additional demands on their time. The inclusion of this item on the CAT-S will therefore allow discussions between staff and family caregivers to take place so that the necessary information and appropriate support services can be provided.

Having a break from caregiving (respite care)

The findings from this study suggest that respite care is an important support mechanism for the family caregivers of stroke survivors. Similarly, ensuring that family caregivers can access a break from caring was one of the most prioritised area identified in the 2018 annual carers survey (Carers UK, 2018). During the first part of the exploratory phase of the current study, family caregivers emphasised the desire to have respite support to temporarily relieve them of physical and emotional exhaustion, enable them to go shopping and to allow them to go on holiday. These assertions highlight the value of respite care for family caregivers who support stroke survivors and are consistent with those from other studies with this population (Buschenfield,

Morris and Lockwood, 2009; Bastawrous et al., 2015; Torregosa, Sada and Perez, 2018). Additionally, family caregivers from the exploratory phase (first part) of the current study, mentioned barriers that prevented them from accessing respite services. These included lack of knowledge regarding respite services, reluctance from either the family caregiver or the stroke survivor and concerns about the quality of the services. Similar barriers have been highlighted in previous research with stroke family caregivers (Cecil et al., 2011; Gosman-Hedstrom and Dahlin-Ivanoff, 2012; Torregosa, Sada and Perez, 2018).

However, it is disappointing to note that despite respite care being identified as an important support for stroke family caregivers, only four out of sixteen family caregivers from the exploratory phase (part one) of this study admitted to having accessed respite services and only one had ongoing respite support. This finding mirrors the results from the annual Carers UK survey (Carers UK, 2018), where out of nearly 7,000 family caregivers who completed the survey, only 16% were accessing this support. Furthermore, 33% reported that the need to have regular breaks from caring was one of the least likely issues to have been appropriately considered during the formal carer's assessment (Carers UK, 2018). The inclusion of the item regarding respite care on the CAT-S could therefore facilitate early discussions between family caregivers and staff or volunteers to take place and thus assist in overcoming some of the barriers identified in this study and the literature. Furthermore, the accompanying suggested next steps section on the reverse of CAT-S form acts as a prompt to signpost family caregivers to the appropriate services without delay. It is important to note that amongst the stroke-specific tools identified in Chapter 3, only the Carers Assessment

Scale (CAS) (Mackenzie, Holroyd and Lui, 1998) contains an item regarding respite support.

Although respite care was highly ranked in this study, the evidence around respite services among stroke family caregivers remains sparse. For instance, in three previous Cochrane reviews (Ellis et al., 2010; Legg et al., 2011; Forster et al., 2012) and two systematic reviews (Bakas et al., 2014; Cheng et al., 2014) focusing on family caregivers and dyad support interventions within the stroke population, none of the studies included respite care as an intervention. Nonetheless, as reported previously, there is sufficient evidence from this study's findings and other qualitative studies regarding the value of respite support from family caregivers' perspectives as discussed in Chapter 2 (Greenwood et al., 2009b; Strudwick and Morris, 2010; Bastawrous et al., 2015). Since the item regarding respite care was highly rated in the current study and included in the CAT-S, it contributes to the literature regarding the value of respite services among stroke family caregivers. Furthermore, it is important to acknowledge that the provision of respite services may vary in various regions in the UK or family caregivers may refuse the opportunity for respite support. It can however, be argued that the identification of alerts regarding respite support are important to provide evidence to inform policy and commissioning of respite services.

Family caregivers' relationship with professionals

As illustrated in Table 34 (Chapter 7), two items regarding family caregivers' views of their relationship with professionals were highly rated in this study (items ranked eighth and tenth). The first item relates to the lack of support given to family caregivers by

professionals. The second relates to the failure of health care professionals to involve family caregivers in decision-making by seeking their knowledge and expertise about the stroke survivor. The prominence of the two items in this study suggest that the relationship between professionals and family caregivers is an important area that must be considered when supporting the family caregivers of stroke survivors. The importance of having positive relationships between stroke family caregivers and professionals has been highlighted in previous research (Brereton and Nolan, 2000; Cecil et al., 2011; Ghomzadeh et al., 2015).

The literature suggests that family caregivers usually prioritise the needs of the stroke survivor over their own (Grant, Hunt and Steadman, 2014). However, findings from the current study suggest that family caregivers desire to have their needs attended to by health and social care professionals as co- clients. This finding is echoed by Cameron et al. (2013), whose stroke family caregivers expressed the wish to have their needs considered more routinely across the care continuum particularly if there were persisting support needs. Sadly, in the exploratory phase (part one) of this study, most family caregivers described feeling abandoned by professionals. Similar findings have been reported in other UK studies (Brereton and Nolan, 2000; Murray et al., 2003; Cecil, 2011) and Canada (Cameron et al., 2013). Brereton and Nolan (2000:504) identified a theme called ‘what about me’ where family caregivers described the lack of attention given to their needs by professionals with the majority not accessing the available support. In previous research, family caregivers who received ongoing support from health care professionals, after the stroke survivor was discharged back into the community, reported improved continuity of care and felt supported

(Cecil et al., 2011; Ghomzadeh et al., 2015).

The failure of professionals to involve family caregivers in decision-making concerning the needs of the stroke survivor appears to be another area of great concern for stroke family caregivers as established from this study's findings. For instance, some family caregivers in part one of the exploratory phase reported 'not being listened to by professionals' (P5). This finding is consistent with those of other studies where stroke family caregivers reported on the failure of professionals to draw on the family caregivers' expertise and identified inadequate consultation and consideration by professionals as areas of concern (Brereton and Nolan, 2000; Simone et al., 2016; Torregosa, Sada and Perez, 2018). The issue is not exclusive to stroke family caregivers as the findings match the results from the annual carers' survey conducted by Carers UK (2018). Amongst the highlighted priorities reported by family caregivers were improvements to be made by the National Health Service (NHS) staff in recognising and valuing the knowledge that family caregivers have and treating them as partners in care by respecting the carer's expertise as co- workers (Carers UK, 2018). It is however apparent from the findings in this study that family caregivers additionally have their own personal needs that must be addressed as co-clients.

In contrast to the other tools identified in Chapter 3, the CAT-S developed in this study is the only tool that contains an item regarding the relationship between professionals and stroke family caregivers. The vital role played by professionals in enabling family caregivers to cope with the demands of caregiving is highlighted in the literature. Professionals have the opportunity to enhance and develop or undermine and ignore

the competencies of the stroke family caregivers, both of which will influence the ability of the family caregiver to cope with the demands of caregiving (Cecil et al., 2011). The inclusion of the item regarding the family caregivers' relationship with professionals on the CAT-S is important as it may enable the family caregivers to have the confidence to initiate difficult conversations relating to issues with professionals.

Advance care planning and end-of-life care

Advance Care Planning (ACP) has been described as a process of communication between patients, their significant others and health providers to understand, discuss and plan ahead for future healthcare management (Sudore et al., 2017). This process informs and empowers patients to have a say about their current and future treatment (DH, 2008; Malpass et al., 2017). In the current study, the item regarding ACP was not highly rated. This finding is not surprising considering that the focus of ACP is on the patient and not the family caregiver. However, as discussed in Chapter 7 (Section 7.11.3), following consultation with the virtual action research group (VAG) and the supervisory team and evidence from existing literature, the item regarding ACP was added as an optional item on the CAT-S (question 10). The main reason for this decision was to capture a wide spectrum of the family caregivers' needs across the stroke caregiving trajectory including family caregivers supporting stroke survivors with palliative care needs living at home. It is important to note that none of the existing stroke-specific tools presented in Chapter 3 contain an item regarding ACP and end-of-life issues. This may potentially limit the use of the tools in instances where the family caregiver is supporting a stroke survivor with palliative care needs.

An additional reason for keeping the ACP item on the CAT-S is that despite advances in the treatment and management of stroke, a large number of patients continue to die from the disease or have subsequent strokes (ISWP, 2016; WHO, 2017), with one in five survivors having another stroke within five years (Mohan et al., 2011). Similar trends were observed in the exploratory phase (part one) of this study, where four out of sixteen stroke family caregivers reported supporting a stroke survivor who had suffered a recurrent stroke. Unfortunately, for individuals who suffer another stroke, the outcomes are poorer than the first stroke (RCP, 2016) and they are also at an increased risk of re-presenting to hospital with life-threatening complications (Malpass et al., 2017). Having conversations regarding ACP may assist in bringing up discussions regarding lasting power of attorney, which could be important if a further stroke impacts on the survivors' mental capacity.

Providing high-quality end-of-life care therefore remains a priority for most national and international stroke guidelines and the importance of ACP has been highlighted in the guidelines (NICE, 2008; Lindsay et al., 2014; ISWP, 2016). Although there is a dearth of stroke-specific studies that have examined the effectiveness of ACP, an Australian study demonstrated improved communication, documentation and awareness of the stroke survivors end-of-life wishes (Malpass et al., 2017). Similar benefits have been reported among individuals with other long-term conditions. Significantly reduced levels of stress, anxiety and depression were observed in studies where family members were involved in ACP and end-of-life discussions, compared to the studies where these conversations did not occur (Detering et al., 2010; Brazil et al., 2018). Most importantly the patient's end-of-life wishes were achieved (Detering et

al., 2010; Kirchhoff et al., 2012).

In view of the benefits of ACP mentioned above, it can be argued that the inclusion of the item regarding ACP on the CAT-S as an optional question is justifiable. This question could act as a prompt for staff and family caregivers to have early conversations regarding ACP with the stroke survivor and increase the likelihood of their wishes being achieved. Additionally, this may assist in minimising the sense of burden when end-of-life decisions are required (Deterring et al., 2010). Furthermore, as established from the current study, it appears that the family caregivers of stroke survivors perceive discussions regarding ACP as appropriate. In the exploratory phase (part one) of this study, the family caregivers highlighted the relevance of the question regarding ACP on the original CAT to their own circumstances. Most suggested that due to their advancing age and that of the stroke survivor, issues regarding end-of-life and ACP are relevant to their situations. This finding concurs with findings from a study by Malpass et al. (2017) who indicated that ACP is both acceptable and feasible during rehabilitation for stroke survivors. Green et al. (2014) propose that compared to acute settings, stroke survivors in non-acute stroke settings have sufficient time to make plans for death and professionals equally have the opportunity to implement appropriate interventions to allow individuals to make decisions whilst able to do so. The inclusion of the ACP item on the CAT-S could therefore allow discussions regarding ACP to be initiated sooner.

Emotional well-being of family caregivers

A surprising finding in this study is the low ranking of the item regarding the emotional

well-being of the family caregivers in Round 2 of the modified Delphi survey. The low rating of this item is contrary to the findings of the literature review as discussed in Chapter 2, where the emotional responses to supporting stroke survivors were highlighted in almost all the studies. Furthermore, the finding contradicts the accounts of stroke family caregivers in part one of the exploratory phase of the current study. As discussed in Chapter 6, there was an overwhelming report from stroke family caregivers of the various negative emotional experiences such as frustration, depression, feelings of abandonment and fear. Similar problems have been highlighted in the literature (Danzyl, 2013; Bastawrous et al., 2015; Masuku, Mophosho and Tshabalala, 2018).

A possible explanation for the low ranking, however, could be the wording of the item as was presented on the Delphi survey. Furthermore, there is evidence from previous research that the family caregivers of stroke survivors may sometimes be reluctant to admit their emotional challenges as this could be viewed as a sign of weakness and thus result in embarrassment (Danzyl et al., 2013). There are also suggestions that the older generation are not as tuned in to emotional distress and its acceptability to admit it (Greenwood et al., 2009b). Similar observations were made in the exploratory phase (part one) of the current study. Some stroke family caregivers were reluctant to seek support regarding their emotional well-being due to fear of being commenced on anti-depressants. This finding suggests a lack of knowledge regarding the treatment options available to family caregivers who experience emotional challenges following stroke. The findings mirror those from a national survey which was conducted by the Stroke Association involving over 2,000 respondents (Stroke Association, 2013). The

survey revealed that although 79% had experienced anxiety and 59% felt depressed, two-thirds did not seek any support, receive any information or advice to help with the anxiety or depression thus further highlighting the prevalence of this problem nationally. Despite these assertions, various treatment options exist alongside medications to support family caregivers following stroke such as counselling and psychoeducation interventions (Cheng et al., 2014; Thomas et al., 2017).

As discussed in Chapter 7, although the item regarding the emotional well- being of stroke family caregivers was not highly rated in the modified Delphi survey, due to the prominence of this item in the literature and the exploratory phase of the current study, the item was included in the CAT-S. The importance of emotional issues following stroke is reflected in both national and international stroke guidelines which state that stroke survivors and their family caregivers must be supported and educated in relation to emotional adjustments (NICE, 2013; Lindsay et al., 2014; ISWP, 2016; SFA, 2017). However, minimal suggestions are provided on how this is to be achieved in the guidelines.

Additionally, the Department of Health, Cardiovascular Disease Outcomes Strategy in the UK, appeals to commissioners and providers to pay particular attention to the emotional and psychological support of stroke survivors and their caregivers (DH, 2013). The Stroke Association further recommend that all family caregivers of stroke survivors should receive a carer's assessment which should include a review of their emotional well-being. Nonetheless, the findings from the current study suggest that carer assessments are not routinely carried out among stroke family caregivers as

discussed in Section 9.3 of this chapter; therefore, it is unlikely that this issue will be addressed via this approach. The inclusion of this item in the CAT-S is important as it will enable family caregivers to be provided with information regarding emotional support and be signposted to appropriate services. Existing literature suggests that assessing caregiver distress and intervening early following stroke may minimise distress (NICE, 2013; ISWP, 2016). The CAT-S, therefore offers opportunities for this to be achieved. It can be argued that due to the high prevalence of post-stroke depression among stroke survivors (Hackett and Pickles, 2014) and the associated interdependence between caregiver and stroke survivor outcomes (Atteih et al., 2015), the monitoring of stroke family caregivers' emotional well-being will remain an important area to focus on in the management of stroke.

9.5 The CAT in comparison with the CAT-S

Although the original CAT was developed with the family caregivers of patients with advanced progressive illness providing end-of-life care at home (Knighting et al., 2015, 2016) some commonalities and differences can be observed between the CAT and the CAT-S. Supporting individuals with stroke and progressive illness are both complex caregiving situations. However, distinct differences exist between the two contexts. While end-of-life trajectories of various diseases such as cancer, dementia or organ failure may vary, typically, progressive illness, has a declining effect on individuals (Murray et al., 2005; Amblas-Novellas, 2016). On the other hand, stroke survivors normally tend to improve over time and the chronic nature of stroke may result in longer-term caring for family caregivers (Lincoln et al., 2011), thus, presenting

different demands on the family caregivers in the two caregiving situations.

Nevertheless, some authors have argued that although caregiving exists in multiple forms and involves supporting people with distinctive needs, there are aspects of caregiving that are common to most family caregivers (Henwood et al., 2017; Social Care Institute for Excellence (SCIE), 2018). This study's findings are in agreement with this observation. Similarities were observed in the original CAT study (Knighting et al., 2015, 2016) and the current study, regarding the ranking of some of the topics. In both studies, the topics concerning the current caring situation (carers as co-workers) and the carers' health and well-being (carers as co-clients) were ranked as the two most important topics. This finding suggests that regardless of the condition of the care recipient, the needs of family caregivers both as co-workers and as co- clients must be considered. Furthermore, end-of-life care was ranked the least important topic in both studies suggesting the tendency of family caregivers in general to focus on the present and not the future. Previous research has reported that the family caregivers of stroke survivors focus on the present as a coping strategy (Greenwood et al., 2009a; Danzyl et al., 2013). Similar observations were made in the first part of the exploratory phase of the current study.

However, despite the aforementioned similarities, there are also some notable differences between the items included on the CAT and the CAT-S under the two main topics mentioned above. For instance, under the current caring situation, one of the priority areas for the family caregivers of stroke survivors include the support required to manage the difficult behaviours of the stroke survivor as discussed in Section 9.4.1

of this chapter. In contrast, patients approaching the end of their life, may exhibit different symptoms with the progression of the disease, including physical deterioration, thus, placing different demands on family caregivers (Hui et al., 2014).

Another main difference between the original CAT and the CAT-S is the item regarding the emotional well-being of the family caregivers. As previously discussed, there is overwhelming evidence in the literature and the current study regarding the effects of caregiving on the emotional well-being of the family caregivers of stroke survivors. The chronic nature of stroke compared with other progressive illness such as cancer has been highlighted as a contributing factor to the high prevalence of psychological distress among stroke family caregivers (Simon et al., 2009). Furthermore, the findings from a national survey by the Stroke Association revealed that 69% of those who had been caring for seven years or more reported stress compared to 48% who had been providing care for up to three years (Stroke Association, 2013). In the current study, some stroke family caregivers were providing care for up to ten years, which further reflects the chronic nature of stroke disease (Lincoln et al., 2011).

A noteworthy finding in the current study relates to the item concerning financial support. As illustrated in Table 33 (Chapter 7), the item regarding the carer's assessment was rated more highly compared to the item regarding financial support, such as benefits and mobility schemes (ranked sixth and thirteenth respectively). This finding is unexpected and will be further explored in the ongoing refinement of the CAT-S, as explained in the next chapter.

9.6 Chapter summary

This chapter aimed to discuss the study's findings in line with the literature discussed in the introduction chapter (Chapter 1) and the two literature review chapters (Chapter 2 and 3), as well as drawing upon the wider body of literature. Similarities and differences between the current study and the literature have been highlighted, with the contributions to knowledge made from this study identified and acknowledged.

This study aimed to adapt the CAT and to develop the CAT-S for use in clinical practice with the family caregivers of stroke survivors. No stroke-specific tool has been previously developed in the UK, therefore the current study aimed to address this gap in the literature and in practice. The resultant CAT-S suggests that the current study met the objectives that were identified in Chapter 3. In the next chapter, the study's strengths and limitations will be explored. This will be followed by discussing the contributions to knowledge developed from this study. Lastly, recommendations for practice, policy and future research are presented, building upon the findings explored within this discussion before drawing final conclusions.

Chapter 10: Conclusion- strengths, limitations and recommendations

10.1 Introduction

The purpose of this chapter is to highlight the study's strengths and limitations thereby adding transparency and credibility to the thesis. The criteria utilised to evaluate the quality of this study will be outlined. This is followed by a summary of the key original contributions to knowledge that have developed from this study. Lastly, the study's main findings are highlighted and presented together with implications for future policy practice, research and policy.

10.2 Evaluating the quality of the study

Various frameworks exist in the literature that are used to evaluate the quality of action research (AR) projects. However, some authors have argued that this may be problematic mainly because AR projects are highly contextual and specific to local areas and thus can only be understood and judged by those directly involved (Reason and Bradbury, 2006; Koch and Kralik, 2006). Nonetheless, despite these assertions, most researchers propose that if AR is to be considered as evidence for practice, then, similar to other approaches (qualitative and quantitative), it must also be open to evaluation (Waterman et al., 2001; Williamson, 2012). Besides, critics who label AR as lacking 'rigour' could use the evaluation to understand the strength of utilising AR to change practice and generate new knowledge (Williamson, Bellman and Webster, 2012).

Given the numerous existing approaches to evaluation, consideration was therefore given to the type of criteria to be used to assess the quality of this study. The decision to use the criteria proposed by Koch and Kralik (2006) was guided by the overall aim of this study, which was to adapt the CAT and to develop the CAT-S for use with the family caregivers of stroke survivors. Unlike other frameworks, which have explicit views regarding the necessity of change in AR studies (Gomm et al., 2000; Waterman et al., 2001; Herr and Anderson, 2005), the criteria by Koch and Kralik (2006) focus on participation as a vital requirement. It was clear from the outset of this study that due to time and resource constraints, it would not be possible to observe the required change in clinical practice. Therefore, as discussed in Chapter 4, the justification for utilising the principles of AR in this study was to allow partnership working between stroke family caregivers and service providers and to develop something tangible (the CAT-S), which would be meaningful to both parties (Koshy, Koshy and Waterman, 2010). It can, therefore, be suggested that this was achieved following the feedback from the pilot of the CAT-S (see Chapter 8).

The key areas for consideration that have been used to assess the quality of this study will be discussed in the next section. Koch and Kralik (2006) present the key area as questions that researchers must consider when assessing the rigour and quality of AR studies (Koch and Kralik, 2006). As discussed in Chapter 4, semi-structured interviews and a modified Delphi survey were utilised to collect data for this study, therefore, additional reference will be made to the consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury and Craig, 2007) and the guidance on conducting and reporting Delphi studies (CREDES) (Jünger et al., 2017). It is

important to note that although the CREDES recommendations were developed in the context of palliative care, in the absence of other existing standards for conducting Delphi surveys, the CREDES recommendations were used to enhance rigour and the transparent reporting of the Delphi survey conducted as part of this study. Full copies of the COREQ and the CREDES are provided in the appendix section of the thesis for further reference to the quality of this study as described earlier (Appendix 28 and 29).

10.2.1 Strengths of the study

What is the worldview?

As proposed by Koch and Kralik (2006), researchers must declare the worldview that drives the research process. It is evident in Chapter 4 of this thesis (methodology) that the study adopted a 'participative worldview'. This criterion resonates with COREQ, which similarly outlines the importance of researchers documenting their methodological orientation (Tong, Sainsbury and Craig, 2007) (see Appendix 28). Furthermore, it is apparent in the three phases of this study that stroke family caregivers were involved in all stages of the CAT-S development. Evidence from existing literature suggests that such active involvement of service users in the research can have a positive impact on the outcomes of the research by ensuring its appropriateness and relevance (Brett et al., 2014). It can also be argued that this 'participative worldview' occurred early in the research process. A consultation exercise (pre-exploratory phase) was conducted with approximately 29 key stakeholders (stroke family caregivers and staff working stroke services and voluntary sector organisations) to establish the value of the study.

Additionally, Koch and Kralik (2006) suggest that it may not always be possible to effect beneficial change in AR studies. Nonetheless, there must be an authentic desire from researchers to secure useful information about people and situations that make a difference to key stakeholders in healthcare, particularly, clients and their communities (Koch and Kralik, 2006). This was achieved through the creation of the virtual action research group (VAG), as described in Chapter 4, whose members were involved in each phase of this study. Their views and comments were valuable in the development of the CAT-S and its potential use in clinical practice.

Is the inquiry credible?

Credibility is another criterion suggested by Koch and Kralik (2006) to evaluate rigour in AR studies. They argue that since participants are part of the validation process, it is important to have their voices adequately represented. This criterion echoes COREQ, which advocates that researchers must state whether the transcripts were returned to participants for checking (Tong, Sainsbury and Craig, 2007) (Appendix 28). Nonetheless, other researchers have contested the benefits of returning transcripts to interviewees and encouraged researchers to weigh the potential advantages and disadvantages of such an activity in their studies. For instance, some participants may wish to change or rephrase large sections of the transcript to refine them (Mero- Jaffe, 2011). Additionally, the time and effort required from participants to contribute to this process has been cited as a disadvantage by other researchers (Hagen, Dobrow and Chafe, 2009).

In this study, the transcripts were not returned to the participants for comments. This

decision was made to avoid overburdening the family caregivers with extra work in addition to their demanding caring role (Stroke Association, 2013; Care UK, 2018). However, in accordance with AR (Kemmis and Mc Taggart 1982; Greenwood and Levin, 2006) this validation process is evident in the involvement of the VAG members in all phases of this study. Additionally, the members of the VAG were clinicians working within stroke services (physiotherapists, stroke consultant), staff working for a charity organisation that supports stroke survivors and their families and stroke family caregivers. It was felt that these participants would provide valuable insight and contribute positively to the key items to be included on the CAT-S. Initially, the VAG was constituted by only one family caregiver, but during the study, the membership was increased to three caregivers to ensure an adequate representation of the stroke family caregivers in the group. Furthermore, all discussions were virtual via electronic communication, which enabled participation from a wider geographical area thus offering a strength to this study. Credibility was therefore enhanced throughout the conduct of this study, as VAG members were invited to provide feedback on various aspects including commenting on the wording and items on the CAT-S. Importantly, VAG members were also asked to comment on the potential use of the CAT-S in clinical practice. This ongoing consultation in AR provides a democratic voice to all participants regarding the best way forward (Meyer, 2010).

Additionally, Koch and Kralik (2006) argue that credibility exists when the multiple voices of participants emerge that are grounded in the data. It can therefore be argued that credibility was also upheld during data collection and analysis. Firstly, during the semi-structured interviews (exploratory and evaluation phase), the participants were

purposefully recruited due to being the family caregiver of a stroke survivor. Furthermore, an interview guide was used during the interviews, which allowed the interviewer to probe and ask questions in relation to the research objectives (Holloway and Wheeler, 2010). Similarly, the recruitment of participants to the Delphi survey targeted staff working within stroke services and stroke family caregivers in their capacity as a 'panel of informed individuals' (McKenna, 1994: 1221), thus allowing contribution to the study from all key stakeholders.

Credibility was further enhanced during the process of data analysis. Data from the interviews were transcribed verbatim and computer-assisted qualitative data analysis software was used to assist with organising the data for easy retrieval (Ritchie et al., 2014). Half of the transcripts from the exploratory phase (eight) were independently analysed by two members of the supervisory team. This was done to enable them to decide if they concurred with the data labels made by the student (themes and sub-themes) thereby enhancing the credibility of the findings.

Similarly, during the conduct of the modified Delphi survey, the recommendations employed by CREDES (Jünger et al., 2017) were adhered to (Appendix 29). This is evident in Chapter 5, where the purpose and rationale for the choice of the Delphi technique are documented. Also provided within this chapter are details regarding the preparatory steps before the survey, piloting of the survey instruments, a flow chart illustrating the stages of the Delphi process and how consensus was achieved throughout the process. Additionally, the results for each round were reported separately as recommended by Jünger et al. (2017) (see Chapter 7).

Is the inquiry transferable?

Koch and Kralik (2006) further propose transferability as another criterion for considering rigour in AR studies. They argue that transferability can be achieved if the readers have enough contextual information, including a profile of the participants, to be able to make a judgement, which may allow the transfer of findings from one situation to the next. This criterion resonates with COREQ (Tong, Sainsbury and Craig, 2007) and CREDES (Jünger et al., 2017), which similarly require researchers to provide a description of the sample and the expert panel respectively. This was achieved in all the phases of this study as evidenced in Chapters 6, 7, and 8. The demographic details of all the participants have been documented in these chapters.

Based on the processes undertaken in this study, it can be argued that the CAT-S demonstrates potential transferability. Nonetheless, drawing upon research on instrument development (Kottner and Streiner, 2014), it is important to acknowledge that claims to transferability are currently tentative due to the small sample during the pilot of the CAT-S. A larger study incorporating the use of the CAT-S with representative samples with test-re-test and inter-rater reliability reporting is therefore required.

Is the study dependable?

Researchers are urged to consider ways in which their inquiry may be dependable, and this can be achieved through the auditing of the research process (Koch and Kralik, 2006). They argue that using systematic processes and maintaining a good record are hallmarks of rigorous research. This has been achieved in the current study

and is evidenced throughout the thesis. Firstly, full details of the narrative literature review are provided in Chapters 2 and 3. Secondly, the recruitment strategies utilised to recruit participants to the different phases of this study have been clearly documented within the methods chapter (Chapter 5). Furthermore, comprehensive details regarding the data analysis process and how the data were managed have been provided. As suggested by COREQ, details of how the data were coded and how the themes were developed have also been included (Tong, Sainsbury and Craig, 2007). In Chapters 6 and 8, the key findings have been presented including quotations from the raw data to illustrate and support the themes arising from the study. Besides, each quotation is identified with the participant number that was given during the interviews, which allows it to be traced back to an individual participant (Tong, Sainsbury and Craig, 2007). As recommended by CREDES, details of how the quantitative data and qualitative data from the modified Delphi survey were analysed are presented in Chapter 5 together with the pre-determined criteria to accept, reject and re- rate an item.

Furthermore, the findings from the three phases of this study are presented in a logical order within this thesis. In Chapter 6, the findings from the interviews are presented, on the basis of which the items of the CAT-S were generated. This is followed by a discussion on how the items were prioritised for inclusion in the CAT-S (Chapter 7). Finally, in Chapter 8, the findings from the pilot of the CAT-S are presented. This is to enable readers to follow the sequence of events on how the CAT-S was developed. Within the discussion chapter, key findings across the three phases of the research are presented to allow conclusions to be drawn from this study.

Is the study believable?

Another criterion regarding rigour proposed by Koch and Kralik (2006) relates to reflexivity. Researchers are encouraged to consider their relationship with the research and its impact on them and their thinking. Furthermore, Koch and Kralik (2006) argue that although researchers are already engaged in the cycles of reflection and action with participants, recording what is going on during the research process is important. This provides the context for the researchers' decisions throughout the research process. During the course of the study, a personal diary was kept by the student where key decisions were recorded. This was particularly based on the findings from each phase of the study as well as the feedback received from the VAG members.

What are the values and interests researchers bring to the inquiry?

Closely related to reflexivity is the requirement for researchers to acknowledge and declare any values and interests that they bring to the study (Koch and Kralik, 2006). Researchers' interests, views and beliefs can affect how research inquiry develops (Denzin and Lincoln, 2011; Silverman, 2017). Koch and Kralik (2006) therefore recommend that in addition to considering the researcher's worldview, their interests and values are recorded and made explicit. This criterion resonates with COREQ, which similarly advocates that the personal characteristics of the researcher are made known including their credentials, occupation, experience and training as well as their reasons for conducting the research (Tong, Sainsbury and Craig, 2007) (Appendix 28). This is evident in the preface section of this thesis, where the research student provides a reflexive account of her previous role as a Clinical Nurse Specialist (CNS)

for stroke and as the Ward Manager of the stroke unit. Furthermore, she acknowledges her personal experiences of having a parent who is a stroke survivor. Her interest in conducting this study are therefore evident. Despite the vast amount of clinical experience working in stroke services, the student had to obtain a career break from full-time employment to become a full-time student. It is obvious that she is a novice researcher and lacked the skills necessary for conducting participatory research. Nonetheless, during the course of the study, various AR training sessions and workshops were attended, thus further demonstrating commitment and interest in the topic. Besides, Koch and Kralik (2006) propose maintaining a journal to record and analyse influences. As stated previously, a personal journal was kept throughout the course of this study.

Is the work accessible?

As proposed by Koch and Kralik (2006), an important feature of AR is the ongoing validation of data and analysis. This is further emphasised by Waterman et al. (2001), who suggest that data analysis in AR becomes a collaborative process of negotiation where findings are fed back to other participants for their contribution and amendment. This was achieved through the VAG, as the findings from each phase of the study were shared electronically to all members for feedback and reflection, as documented in Chapter 5. Additionally, during the conduct of the Delphi survey, efforts were made to ensure that the feedback provided to the participants between the Delphi rounds was in simple language for all participants to understand. Furthermore, the piloting of the questionnaire was undertaken, as recommended by CREDES (Jünger et al., 2017). Minor amendments were made as described in Chapter 5 to ensure lack of

ambiguity in the wording of some items.

Additionally, access to this study's findings was enhanced through dissemination to the wider stroke and research audience. Although the text is co-constructed with the participants, Koch and Kralik (2006) suggest that it is the researcher's responsibility to bring the work together. Findings from the first part of the exploratory phase of this study were prepared and shared by the student locally through a 10-minute oral presentation at the University's Post Graduate Symposium in May 2016 and the Faculty 'work in progress' session in October 2016. Furthermore, a peer-reviewed poster was presented at a national stroke conference in Liverpool in December 2016. Additionally, a summary of the key findings from the exploratory phase of this study, was developed and shared electronically with staff at the three sites that were used to recruit participants, thus further enabling the accessibility of this study's findings. Two papers are currently in preparation for publication in appropriate journals. A notable strength of this study is the grant secured to pilot the feasibility of recruitment, the usability and usefulness of the CAT-S with a larger number of stroke family caregivers and staff working within stroke services in Liverpool. The student was part of the team that developed a competitive funding application to pilot the CAT and the CAT-S locally. The grant application was supported by clinicians and staff working within stroke services and additionally patient and public involvement was sought. The application was peer reviewed by external academics, thus indicating the perceived value of the CAT-S in supporting stroke family caregivers. See Appendix 33 for the letter confirming the funding.

10.2.2 Limitations of the study

Despite the above-mentioned strengths, as is the case with most research, there are some limitations evident in this study. Firstly, the stroke family caregivers who took part in the interviews in the first phase were all white and mainly spousal family caregivers. Additionally, the majority were older and retired. These findings may therefore not be representative of other caregivers, who are not spouses or younger caregivers with additional responsibilities such as young children and employment. Moreover, minority populations were not represented in these interviews. This potentially limits the transferability of the findings.

Additionally, it is recognised that the sample size in this study is small and this creates further limitations regarding the generalisability and transferability of the findings to all family caregivers of stroke survivors. However, the data collected provide important insights into the experiences of the family caregivers of stroke survivors that have implications for practice and future research. Also, the results confirm the previous findings regarding the challenges experienced by caregivers who support stroke survivors (Han and Haley, 1999; Greenwood et al., 2009a). In terms of tool development, it can be argued that this limitation did not affect the overall development of the CAT- S, as the survey items were generated from both the study's findings and the wider stroke literature.

The second limitation of this study is the low response rate particularly from the stroke family caregivers' cohort during the modified Delphi survey. As described in Chapter 5, the recruitment strategy for both the family caregivers and the staff cohort was

reliant on gatekeepers. Although relying on gatekeepers can sometimes be a positive recruitment strategy, this approach also has some limitations (Bonevski, 2014). For instance it is difficult to establish whether or not reminder emails were sent by gatekeepers to enhance response rates for the web-based surveys in the current study. Furthermore, it is evident in Chapter 7 that the recruitment of family caregivers to participate in the modified Delphi survey proved difficult, and as a result, the anticipated number of participants was not achieved despite extensive efforts being made. It is possible that the gatekeepers may not have prioritised the survey over their workload (Whittingham, 2016). In addition, due to the recruitment strategy described in Chapter 5, it is not possible to determine the exact population size from which the sample was recruited. It is unknown how many questionnaires were distributed to the family caregivers to reliably calculate the response rate.

As recommended by CREDES, response rates must be reported over the ongoing iteration (Jünger et al., 2017). Likewise, gatekeepers were also utilised to recruit staff to the survey, therefore, it is unknown how many members of the recruiting organisations received the invitation email and met the inclusion criteria to calculate the response rate. Surveys are generally associated with low response rates (Bowling, 2014; Polit and Beck, 2017). Similarly, Delphi surveys are infamous for their response rates lowering as rounds increase (McKenna, 1994; Keeney, 2015). Upon reflection, a different recruitment strategy with less reliance on the gatekeepers would have perhaps yielded favourable results. Keeney, (2015) advocates gaining the commitment of potential participants before the commencement of the study as a means of enhancing response rates in Delphi surveys as this promotes ownership of

the study. The study could have been advertised through the gatekeepers inviting those members who are interested in participating in the survey to contact the researcher directly. This would have enabled direct contact with interested individuals without reliance on gatekeepers. Furthermore, this would facilitate a reliable calculation of the response rate and follow-up on non-respondents (Keeney, Hasson and McKenna, 2011).

Additionally, the recruitment of family caregivers to participate in the Delphi survey was further affected by another study taking place in the area at the same time (see Chapter 7). Highlighting the recruitment challenges encountered in this study is important as this can inform similar research in the future. For instance, checking and confirming with the recruitment sites about their research plans or involvement in other studies as early as possible could have resulted in the student avoiding these sites.

With regard to the CAT-S developed in this study, it can be argued that due to the low response rate mainly from the family caregivers, it is possible that this skewed and possibly influenced the final selected items. Additionally, the pilot study and subsequent evaluation phase had a very small sample size, and this creates limitations regarding the significance of the study. Although this may limit the ability to draw definite conclusions and global recommendations regarding the usability of the CAT-S in practice, the ongoing nature of action research provides a platform for further action research cycles (Carr and Kemmis, 1986; Waterman et al., 2001, Meyer, 2006). As stated, funding has been secured to conduct additional work on the CAT-S. Further consultation with the stroke family caregivers and staff working within stroke services

in Liverpool took place between October and December 2018. The piloting of the CAT-S with a large number of stroke family caregivers is currently ongoing.

Establishing the reliability of a scale or tool is an important step in instrument development (Kottner et al., 2011; Streiner, Norman and Cairney, 2015). It is important to note that the CAT-S developed in this study is a new tool that has not undergone psychometric testing including reliability studies. Reliability relates to the ability to achieve similar results with repeated measures and is usually established by performing a test-retest (Abell and Kamata, 2009; Kottner et al., 2011). This examines the variability associated with repeated measurements of the same phenomena at different points in time. Another limitation is that the CAT-S was only piloted to test feasibility of recruitment, methods of data collection and its usability and usefulness in practice. No reliability studies to establish the test-retest reliability and the interrater reliability of the CAT-S have been conducted. To address this gap, further studies are warranted.

10.2.3 Summary of the strengths and limitations

In the first section of this chapter, the study's strengths and limitations have been considered based on questions regarding rigour as proposed by Koch and Kralik (2006), the COREQ (Tong, Sainsbury and Craig, 2007) and CREDES (Jünger et al., 2017). In the next section, a summary of the contributions to knowledge developed from this study will be presented.

10.3 Original contributions to knowledge

As noted in Chapter 3, stroke-specific evidence-based screening tools for use with the family caregivers of stroke survivors are currently lacking. Furthermore, none of the identified tools were developed in the UK, thus potentially limiting their use with stroke family caregivers locally. The overall aim of this study was therefore to adapt the CAT and from it, to develop the CAT-S for use with the family caregivers of stroke survivors in the UK. The CAT-S developed in this study addresses this gap. It is the first stroke-specific tool to be developed in the UK for use with the family caregivers of stroke survivors and thus adds to the list of the stroke tools discussed in Chapter 3. Since the items on the CAT-S are supported by existing literature, it has the potential for transferability to other countries, particularly if tailored to local services, however, this will require further exploration in future research.

It should be noted that since the development of the original CAT, the current study is the first to widen the use of the CAT to other populations. The feedback received during the CAT-S pilot with community-based stroke coordinators and stroke family caregivers as highlighted in Chapter 8 suggests that the CAT-S has the potential to identify the needs of stroke family caregivers and ensure that they receive timely support. Furthermore, as stated earlier, external funding has been awarded to pilot the feasibility of recruitment, the usability and usefulness of the CAT-S with a larger number of stroke family caregivers. The pilot is being supported by a national stroke charity and data collection has been completed at one of their sites. A total of four sites in the North-West will be involved in the pilot. Data collection at the three remaining

sites has since commenced following ethical approval (National Health Service (NHS) ethics) being granted. The application for external funding underwent a peer review process and therefore provides some confidence regarding the viability and usefulness of the CAT-S for the family caregivers of stroke survivors.

It is important to note that in comparison with existing tools, as previously discussed in Chapter 9, the CAT-S contains other items and topics that despite being highlighted in the literature have not been included in other tools. These include items concerning the family caregivers' coping strategies, their relationship with health and social care professionals, contingency plans during an emergency, demands on their time in addition to caring and an item regarding ACP and end-of-life care. The CAT-S is therefore unique, yet as previously discussed under the limitations section of this chapter, further consultation and development of the CAT-S is required before it can be embedded into practice.

As discussed in Chapter 3 (Section 3.8), during the development of the identified tools, there was minimal consultation and involvement of stroke family caregivers and staff working within stroke services regarding the selection of items to be included in the tools. The perspectives of staff and stroke family caregivers are required to ensure that the tool is relevant to the needs of practitioners and family caregivers and not just researchers. It can therefore be argued that the CAT-S represents the first stroke-specific evidence-based tool to be developed collaboratively with staff working within stroke services and stroke family caregivers utilising consensus methods and principles of action research. This study provides an original contribution to existing

knowledge in terms of collaborating with family caregivers when selecting items during tool development utilising consensus methods.

Furthermore, the current study contributes to methodological knowledge. The modified approach to action research utilised in this study as discussed in Chapter 4 of this thesis, enabled the formation of a virtual action research group (VAG), which was consulted in all the phases of this study. The VAG assisted in ensuring that the CAT-S was relevant to both staff and the family caregivers of stroke survivors. Finally, the findings across the three phases of this study have highlighted some of the current shortfalls in practice. The findings therefore add to the existing literature about the challenges that the family caregivers of stroke survivors continue to experience in the UK despite changes to the legislation and key policy drivers.

10.4 Recommendations for policy, practice and future research

In the next section, some recommendations for policy, practice and further research will be provided based on this study's findings.

10.4.1 Recommendations for policy

National stroke guidelines in the UK (ISWP, 2016) recommend that the family caregivers of stroke survivors are offered an assessment of their own needs separate from those of the stroke survivor. They further highlight some of the key areas of support that require consideration by the staff who come in contact with the family caregivers of stroke survivors (Figure 10). No suggestions are however provided in

the guidelines on how these recommendations can be achieved in clinical practice. Despite these recommendations, this study's findings indicate that the needs of stroke family caregivers are not consistently assessed in clinical practice. Furthermore, considerable delays of up to six months were noted for some family caregivers to have an assessment completed. Based on the findings from this study, it can therefore be argued that utilising a triage tool such as the CAT-S in clinical practice offers some opportunities for staff to assess the needs of stroke family caregivers. As established from the pilot, the CAT-S can be easily completed by non-registered staff, such as community-based stroke coordinators, thus making the assessment of stroke family caregivers' needs more accessible. This will potentially allow the recommendations contained in the guidelines to be achieved.

Figure 10: Stroke - support for stroke family caregivers (ISWP, 2016: 31).

When care is transferred out of hospital to the home or care home setting, the carer of a person with stroke should be offered:

- An assessment of their own needs separate to those of the person with stroke.
- The practical or emotional support identified as necessary.
- Guidance on how to seek help if problems develop.

The primary carer(s) of a person with stroke should be provided with the contact details of a named healthcare professional (e.g. a stroke co-ordinator) who can provide further information and advice.

After a person with stroke has returned to the home setting, their carer should:

- Have their need for information and support reassessed whenever there is significant change in circumstances (e.g. if the health of the carer or of the person with stroke changes).
- Be reminded and assisted in how to seek further help and support.

10.4.2 Recommendations for practice

It is evident from the study's findings that despite changes to legislation, knowledge

gaps regarding carers' assessment still exist among family caregivers. It was noted that some caregivers are not aware of their right to assessment whilst others appeared to confuse the social services carers' assessment with assessments for financial benefits such as attendance allowance. A recommendation for practice is therefore for staff working within stroke services to ensure that the families who support stroke survivors are educated about their rights to assessment to enable them to seek timely support when required. It can also be argued that since the CAT-S contains a question regarding carers' assessment, this can provide an opportunity for staff to clarify to the family caregivers what a carer's assessment is and the family caregivers' right to assessment.

Based upon the findings from this study, it is clear that, in addition to active coping strategies, some stroke family caregivers may utilise passive coping strategies depending on their personal circumstances. Passive coping strategies are associated with poorer outcomes, such as depression for stroke family caregivers (Rochette 2007; Visser-Mieley et al., 2009). Therefore, a recommendation for practice is that, if applicable, the family caregivers of stroke survivors should be taught how to actively cope with the consequences of stroke. This may be provided by existing services such as community psychotherapy services.

10.4.3 Recommendations for future research

Although a number of important findings have been generated from the study, it is apparent that future research on interventions to support stroke family caregivers is required. However, based on the findings from this study, it is evident that stroke family

caregivers experience challenges, particularly with managing their own emotions. It would therefore be useful for future research to focus on interventions that would assist stroke family caregivers in managing their emotions.

During the pilot of the CAT-S, it was noted that family caregivers' needs were identified and that participants received timely support. This finding suggests that the CAT-S has the potential to improve the health and well-being of stroke family caregivers. It is therefore recommended that further refinement and piloting of the CAT-S with a larger population of family caregivers is required before recommendations regarding its use in clinical practice can be made. The piloting of the CAT-S with a larger stroke population is currently underway. Furthermore, the CAT-S requires further clinical testing for sensitivity and specificity i.e. test retest and interrater reliability (Streiner and Kottner, 2014).

10.5 Conclusion

The majority of stroke survivors rely on their family caregivers for support to continue living at home, but it is clear from this study's findings that stroke family caregivers experience considerable challenges as a result of providing care. Additionally, the findings from this study have highlighted shortfalls to the existing approaches to supporting the family caregivers of stroke survivors. For example, the majority of stroke family caregivers had not completed a carer's assessment while others lacked knowledge about the carer's assessment and their rights to the latter. Furthermore, delays of up to six months were noted among some carers in completing a carer's

assessment.

It is therefore argued that the CAT-S developed in this study has the potential to improve the support provided to the family caregivers of stroke survivors. The findings from the CAT-S pilot suggest that it offers opportunities to non- clinical staff working in voluntary sector organisations who have regular contact with stroke family caregivers to identify the needs of the family caregivers and signpost them to various services for relevant support. Recommendations for policy, practice and research have been proposed, which could be useful in improving the health and well-being of family caregivers who support stroke survivors.

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Appendices

Appendix 1: Original Carer's Alert Thermometer (CAT)

Carers' Alert Thermometer (CAT) V1.1

Edge Hill University

INSTRUCTIONS

Section 1 and 2 to be completed with the carer, ticking the risk level of any alerts to (a) the care being provided or (b) carers well-being;

L NO or LOW risk I INTERMEDIATE risk H HIGH risk

Section 3 circle the total number of **intermediate** (amber) and **high risk** (red) alerts on the thermometer;
Section 4 make a plan with the carer prioritising the top four alerts for action, and note the agreed appropriate action for the alerts identified;
Section 5 set a review date and person responsible for follow up. All questions to be revisited during a review to monitor for any change. It is recommended that monitoring and review dates be more frequent for carers with alerts which are considered 'HIGH' (**red**) or 'INTERMEDIATE' (**amber**).

Date CAT conducted:..... By (Staff name):.....**Tel:**.....

SECTION 1: PLEASE COMPLETE THE DETAILS OF THE CARER & PERSON BEING CARED FOR

Carer's Name: ..... Relationship to cared for person:.....

Name of person caring for:..... D.O.B.:..... NHS No.:.....

Address & Tel:.....

GP of cared for person:.....

Other key professional contact (if app):.....

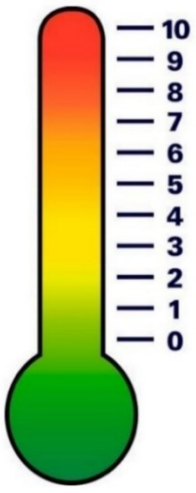
Carer address & Tel (if different):.....

SECTION 2: IDENTIFY & ASSESS THE NEEDS OF THE CARER

Discuss the following areas with the carer to identify any alerts requiring action. [x] = person being cared for e.g. husband or wife.

(A) CURRENT CARING SITUATION Q1) Do you have any needs or concerns about caring for your [x]?	L I H
Q2) Do you need any information about the condition your [x] has and how the care needed might change over time?	L I H
Q3) Do you need any help to provide any of the physical or general daily care your [x] requires?	L I H
Q4) Do you need any help to provide any emotional or spiritual care your [x] requires?	L I H
Q5) Do you have a named person to call in an emergency or out-of-hours to discuss any concerns about your [x]?	L I H
(B) CARER'S HEALTH AND WELL-BEING Q6) Do you feel involved in discussions and listened to by professionals about the care needed by [x]?	L I H
Q7) Do you need any help or information about money or legal issues?	L I H
Q8) Do you need a break from caring during the day or overnight?	L I H
Q9) Do you need any help to balance your own needs with the demands of caring? *(e.g. attend own health appointments, social activities)*	L I H
If appropriate include: Q10) Do you know your [x]'s wishes and preferences for EoL care? (If known, have they been written down and shared, e.g. advance care planning (ACP) doc?)	L I H

SECTION 3.
CIRCLE THE TOTAL NUMBER OF ALERTS ON THE THERMOMETER



Carers Alert Thermometer _ Version 1.1 © **Edge Hill University** Any correspondence to eprc@edgehill.ac.uk Further information is available at www.edgehill.ac.uk/carers

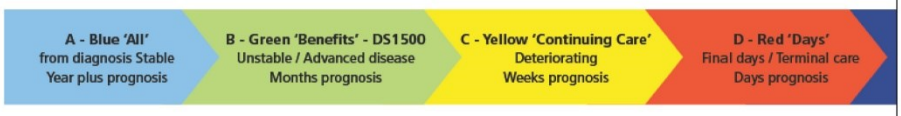
SUGGESTED NEXT STEPS Some general guidance is included below which can be amended by managers or senior clinicians of the service to help guide staff responses when conducting the CAT based on available local services and support.

Q1	If no needs raised with this opening question continue with the rest of the CAT.
Q2	Provide information to the carer if appropriate or refer to the appropriate professional.
Q3	Identify area of need, provide advice if appropriate. If needed, proceed to full assessment.
Q4	Discuss local & national sources of support for the carer & advise on routes of support for the patient e.g. GP
Q5	Identify if person cared for has a named professional for O-O-H contact. Advise on appropraite O-O-H support.
Q6	Discuss carer's concerns; if appropriate, liaise with appropriate health & social care professionals.
Q7	Provide information on local services e.g. local carer centre/ Citizen's Advice Bureau/Macmillan Cancer Support. If needed, proceed to full assessment.
Q8	Provide information about local respite care or sitting services. If needed, proceed to full assessment.
Q9	Provide information about local services and support e.g. carer centre. If needed, proceed to full assessment.
Q10	If appropriate, ask if they would like information on Advance Care Planning. If needed, proceed to full assessment.

SECTION 4: PLAN. Use this table to briefly note the details of each priority alert, any actions taken, and any next steps which have been agreed with the carer

Brief summary of needs identified by alerts (If there are several needs, ask the carer to "*identify which one thing would help you most at this time?*")	**Any immediate action taken** e.g. information clarified, verbal or written information given, referred to see other health care professional	**Any next steps required?** e.g. Referral to other services, speak to Team Leader/Manager for advice on next steps	**Who is responsible for the next step or follow up?**

SECTION 5: Date of next review:…… with……

If possible, please give an indication of the GSF indicator stage of the person being cared for by circling the most appropriate stage:	

Appendix 2: Search strategy

Strategy 504914

#	Database	Search term	Results
1	AMED	(stroke OR "cerebrovascular accident").ti,ab	8239
2	AMED	(care* OR caregiver* OR famil* OR spouse*).ti,ab	42888
3	AMED	(1 AND 2)	1403
4	AMED	(challenges OR experiences OR concerns).ti,ab	10747
5	AMED	(3 AND 4)	90
6	AMED	5 [DT 2000-2018] [Languages English]	78
7	BNI	(stroke OR "cerebrovascular accidents").ti,ab	8298
8	BNI	(care* OR caregiver* OR famil* OR spouse*).ti,ab	263324
9	BNI	(7 AND 8)	2743
10	BNI	(challenges OR experiences OR concerns).ti,ab	64809
11	BNI	(9 AND 10)	272
12	BNI	11 [DT 2000-2018]	269
13	CINAHL	(stroke OR "cerebrovascular accident").ti,ab	71118
14	CINAHL	(care* OR caregiver* OR famil* OR spouse*).ti,ab	853793

15	CINAHL	(13 AND 14)	12035
16	CINAHL	(challenges OR experiences OR concerns).ti,ab	375862
17	CINAHL	(15 AND 16)	1746
18	CINAHL	17 [DT 2000-2018] [Languages eng]	1653
19	Medline	(stroke OR "cerebrovascular accident").ti,ab	208909
20	Medline	(care* OR caregiver* OR famil* OR spouse*).ti,ab	2239942
21	Medline	(19 AND 20)	26856
22	Medline	(challenges OR experiences OR concerns).ti,ab	504504
23	Medline	(21 AND 22)	1395
24	Medline	23 [DT 2000-2018] [Languages English]	1294
25	PsycINFO	(stroke OR "cerebrovascular accident").ti,ab	30091
26	PsycINFO	(care* OR caregiver* OR famil* OR spouse*).ti,ab	734420
27	PsycINFO	(25 AND 26)	5233
28	PsycINFO	(challenges OR experiences OR concerns).ti,ab	381847
29	PsycINFO	(27 AND 28)	526
30	PsycINFO	29 [DT 2000-2018] [Languages English]	500

Appendix 3: Summary of qualitative studies (n=37)

Authors / Year	Country	Participants details (relationship to stroke survivor, ethnicity, age and duration in caregiving role in months/ years	Methodology/ data collection	Key findings	QA (CASP)
Backstrom and Sundin, 2009	Sweden	N=9 (7 females, 2 males). Mainly spouses but sample also included parents. Ethnicity not stated. Age range 41-65; median age 55. Family caregivers providing care up to one year following the stroke survivors discharge from hospital.	Qualitative >Narrative interviews >Sample interview questions provided	Family caregivers reported challenges dealing with the personality changes among stroke survivors. They also reported struggling with health providers for visibility and confirmation. Movement from self-denial to self-recognition in search of their own well-being was highlighted by the participants. Financial challenges were mentioned. Employment and support from family members helped them to cope.	15/20
Backstrom and Sundin, 2010	Sweden	N=9 (7 females, 2 males). Mainly spouses but sample also included parents. Ethnicity not stated. Age range 40-64; median age 54. Family caregivers providing care up to six months following the stroke survivors discharge from hospital.	Qualitative >Narrative interviews >Sample interview questions provided	Family caregivers reported feeling unprepared and tired. They also reported feeling neglected by professionals and isolated. Participants struggled with managing their own emotions following the realisation that life will never be the same.	15/20
Bakas et al., 2002	USA	N =14 (all female family caregivers; seven daughters, four spouses and three other relatives). Ethnicity: Eight African American and six white). Age not stated. Caregivers were providing care within six months after hospital discharge.	Qualitative >Telephone semi-structured interviews >Interview schedule provided	Five main concerns and needs reported include: information about recurrent stroke, emotions and behaviours of the stroke survivor, concerns about providing physical care, increasing expenditures and managing their own responses to caregiving (e.g. isolation, their own emotions and their own physical health).	16/20

Bastawrous et al., 2015	Canada	N=23 (all adult daughters aged between 38-54 years). Ethnicity not reported. Daughters had been providing care for a median of 6 months.	Qualitative >Semi-structured interviews >Interview guide provided	Caregiving -related role overload affected other valued relationships such as being a wife or mother at the same time resulting in heightened stress. Caregiving affected the daughters' participation in valued activities such as employment, leisure activities as well as physical space due to relocation to live with their parent who suffered stroke. Participants reported the need for respite to help them cope.	18/20
Brereton and Nolan 2000	UK	N=7 (2 males and 5 females) All spouses aged between 65-84 years. Ethnicity not reported. Providing care between 2 and 4 years.	Qualitative >In-depth, semi-structured interviews >Interview questions or topics not provided	Four main themes identified: What's it all about (lack of information about stroke, the caregiving role and where to seek support e.g. financial support), Going it alone (isolation and searching for information themselves), Up to the job (need to feel competent to provide physical care), What about me (lack of attention given to caregivers needs and failure of professionals to draw on caregivers' knowledge about the stroke survivor which appeared to reduce the effectiveness of care delivered.	12/20
Bulley et al., 2010	UK	N=9 (7 females, 2 males) All spouses, White British aged between 55-74 years, caring for stroke survivors between 2-7 years post-stroke	Qualitative >Semi-structured interviews >Interview questions provided.	Family caregivers reported that their lives turned upside down. They experienced increased caring and domestic workloads, reduced social participation. Emotional and behavioural changes in their spouses impacted on their own emotional well-being reporting stress, anxiety, depression and loneliness.	18/20

Buschenfield, Morris and Lockwood, 2009	UK	N=7 (3 females, 4 males). All partners of the stroke survivor. All White British/European origin. Age between 49- 62 years. Providing care between 2 -7 years post -stroke.	Qualitative >Semi-structured interviews >Topics contained in the interview guide provided.	Partners reported changed lives and taking on most of the household task in addition to providing care. They also reported the enduring impact on the quality of the relationship. Taking up or giving up employment was a challenge as well as restricted social life. Emotional impact of the stroke was reported as overwhelming and enduring. Strain and exhaustion from the disruption of routines was also a challenge.	17/20
Cameron et al., 2013	Canada	N=24 (17 females, 7 males). Majority were spouses, but sample also included some adult children. Ethnicity not stated, aged between 36-77; mean age 65.5. Duration of caring 1-134 months; mean duration 11 months.	Qualitative >Face to face and telephone semi-structured interviews. >Sample interview questions provided	Support needs reported by family caregivers included information about secondary stroke prevention, community support services for caregivers, emotional support, respite care and peer support groups.	15/20
Cecil et al., 2011	Northern Ireland	N =10 wives to the stroke survivor. Age reported as middle-aged or older. Caring for husbands who had suffered stroke the previous 8 years. Ethnicity not reported.	Qualitative >Semi-structured interviews and a focus group discussion >Interview topics provided	Lack of information and training to provide care, lack of support from family and friends, physical strain of caring and worries about the future were challenges reported by participants.	15/20
Chow and Tiwari, 2014	Hong Kong	N=29 (21 females and 8 males). 17 were spouses and 12 were adult children. Ethnicity not reported. Caregivers age ranged from 42- 87 year. Most caregivers were providing care for more than four years.	Qualitative >Focus group discussions >Topics on the interview guide provided	Family caregivers reported adverse impact on their physical health, psychological health, financial hardship and pressure created by cultural expectations. Support needs identified by the caregivers included: education and training on how to care for the	14/20

				stroke survivor and improvement of existing services.	
Coombs, 2007	Canada	N=8 (5 females, 3 males). All spousal caregivers. Ethnicity not reported. Age between 57-81 years. Duration of caregiving ranged from 1.5 to 5 years.	Qualitative >Semi-structured interviews >Sample questions or topics on the interview guide not provided	Family caregivers reported profound sense of loss (loss of leisure time, loss of freedom, loss of marital relationship). They also reported taking on new responsibilities that were previously done by the stroke survivor. Physical and emotional demands associated with caregiving as well as uncertainty for the future. Caregivers reported having to depend on other family members for support.	15/20
Danzyl et al., 2013	USA	N=12 (7 females and 5 males). Half were spouses and half were adult children. Ethnicity: All were white aged between 38-75, mean age 55.9 years. Providing care to survivors 1-14 years post stroke; mean years 3.6.	Qualitative >Semi-structured interviews >Sample questions on the interview guide provided	Participants reported challenges with accessing rehabilitative care in their rural communities. They also reported the need for psychological support, caregiver support groups and respite care. Changing life roles and challenges to re-integrating into life and rural communities were also mentioned.	18/20
El Masry, Mullan and Hackett, 2013	Australia	N =20 (16 females, 4 males) 15 spouses, three siblings and two adult children. Ethnicity: Almost half were Anglo-Australian, the sample also comprised of Europeans from both English and non-English speaking countries, South American and South East Asian aged between 31-90. Caregivers were providing care for at least 3 months.	Qualitative >Semi-structured interviews >Topics or questions contained on the interview guide not provided	Challenges included changed relationships with the stroke survivor and other family members. Family caregivers also reported depressive emotional patterns with older caregivers expressing health problems more than the younger caregivers. Managing the cognitive and behavioural changes of the stroke survivor was reported as a challenge	16/20

				for the caregivers including employment, financial strain and lack of social support.	
Gholamzadeh et al., 2015	Iran	N=17 (all female; 9 daughters and 8 daughters-in-law). Ethnicity not stated. Age ranged from 26 – 60 years; mean age of 36.4 years. Data collected at one-month post-hospital discharge.	Qualitative >Focus group discussions and semi-structured interviews >Examples of questions and topics on the interview guide provided	Support needs and challenges reported included information and training, financial support, the need for support to provide care, maintenance of their own physical and emotional health; poor communication with health care professionals and adjusting with cultural obligations to provide care for parent-in-law.	17/20
Gosman-Hedstrom and Dahlin-Ivanoff, 2012	Sweden	N=16 female spousal caregivers aged between 67-83 years. Providing care between 2 and 15 years. Ethnicity not reported.	Qualitative >Focus group discussions >Examples of topics on the interview guide provided	Changes in partners' personality, loss of a life companion, fear of recurrent stroke, confinement, negotiating time to oneself due to tiredness, lack of formal support, lack of information/training to provide care.	17/20
Greenwood et al., 2009a	UK	17 articles	Systematic review of qualitative studies >MEDLINE, CINAHL, EMBASE, BNI, HMIC, AMED, ASSIA.	Commonly identified challenges included information needs about stroke; training and skills to provide care, information needs about financial entitlements; caregivers emotional responses to caregiving and the need for emotional support; role and relationship changes and uncertainty about the future.	17/20
Greenwood et al., 2009b	UK	N=31 (22 females, 9 males; 16 spouses; 13 adult children and 2 siblings) Ethnicity: Majority were White British, but sample also comprised of other white, Asian and Black caregivers with the majority	Qualitative >In-depth interviews at three time points: close to discharge, 1 month and approximately 3	Uncertainty was a central theme throughout for both new and established caregivers. They reported uncertainties regarding formal support, paid employment, as well as health	15/20

		aged 66 years or over. Caregivers providing care within the first three months after discharge from hospital	months after returning home. >Interview guide or topics not provided	changes and behaviour of the stroke survivors.	
Katbamna et al., 2017	UK	N=18 (12 females and 4 males). Sample comprised of spouses and adult daughters. Ethnicity; 12 White British and 6 British Asian Indian. Majority were over 60 years old.	Qualitative >In-depth interviews at one month and 3-6 months post stroke. >Examples of interview questions provided.	Family caregivers emotional and physical well-being was undermined by the uncertainty and unpredictability of caring. The strain of managing social obligations was common to all caregivers irrespective of gender and ethnicity.	14/20
Kerr and Smith, 2001	UK	N=22 (13 females, nine males). More than half were spouses, but sample also included adult children and a daughter-in-law. Ethnicity not stated. Age between 21-90. Caregivers had been providing care for up to one year.	Qualitative >In-depth interviews >Topic guide used at interview provided	Caregivers reported lacking physical skills to provide care, dramatic change in their own lifestyle. They also reported loneliness and feeling emotionally drained. Financial support and wanting a break from the caring role were also identified as support needs by the caregivers.	12/20
King and Semik, 2006	USA	N=93 (Majority were females; 67% and spouses to the stroke survivor; 89%. The sample was predominantly White (75%). Age range 22 to 85; mean age 56.7. Data was collected at T1 (during stroke survivor hospitalisation), T2 (first 2-3 months at home), T3 (the remainder of the first year) and T4 (at 2 years post stroke).	>Qualitative (part of a mixed method study) >Semi-structured interviews >Questions on the interview guide provided	The hospitalisation period and the first months at home were the most difficult for 76% of the family caregivers. Unmet needs were related to caregiver preparation, promoting the function of the stroke survivor and sustaining the self and family. Uncertainty, new responsibilities and the stroke survivors' impairments were identified most often usually early during caregiving.	12/20
Lee, 2004	Hong Kong	N=15 (10 females and 5 males). Twelve spouses and three adult children. All Chinese aged between	Qualitative >In-depth interviews >Interview questions or topics not provided	Main challenges included learning to cope with new demands (particularly providing physical care including personal care and toileting); Managing	11/20

		27-87 and supporting the stroke survivor for more than six months.		one's own emotional responses; Lack of support from professionals and family and maintaining a balance between caregiving and one's own needs.	
Lin, 2010	USA	N=40 (35 female, 5 males). Half were spouses, the relationship of the other half not stated. All were Chinese American with the exception of two who were Caucasian. Age range 51-87. Duration of caring less than a year up to 27 years.	Qualitative >In-depth, semi-structured, open-ended interviews >Interview questions provided	The main challenges reported were: the impact and adjustment in lifestyle for the caregiver; lack of social activities and support; physical and mental stress. Lack of access to accurate and culturally sensitive information concerning care of the stroke survivor was also highlighted. Depression and lack of societal groups were most common.	10/20
Lopez-Espuela et al., 2018	Spain	N=18 (5 male spouses and 13 female spouses). Ethnicity not reported. Age range between 42-80 years; mean age 55 years. Caregivers had been providing care between 5 -102 months; mean duration 28.72 months.	Qualitative >In-depth interviews >Interview guide provided.	Caregivers reported feeling forced to live behind a normal life and focus on the stroke survivors care. They also reported the need for respite to allow the caregivers to recover their previous identity. Spouses reported taking on a predominant role as a caregiver due to physical, cognitive emotional and behavioural change of the stroke survivor. This also affected their relationship with the stroke survivor.	17/20
Masuku, Mophosho and Tshabalala, 2018	South Africa	N=14 female primary caregivers (wives, daughters and daughters-in-law) of stroke survivors with aphasia. Ethnicity not stated. Aged between 21-65 years, providing care between 3 months and 3 years.	Qualitative >Semi-structured interviews >Examples of topics under the five sections of the interview guide provided	Frustrations due to lack of information and strategies to facilitate communication. Lack of social and financial support from family members. Emotional and psychological difficulties. Other challenges reported include feminisation of caregiving.	17/20

Moore et al., 2002	USA	N=8 (5 females and 3 males). Participants were spouses, adult children and a sibling. Ethnicity: not stated. Age range between 30- 80 years. Duration of providing care not reported.	Qualitative >Semi-structured, telephone interviews > Sample questions on the interview guide provided	Caregivers reported having 'no life' due to the demands of caregiving. Other challenges reported included uncertainty regarding the future, overwhelming nature of physical tasks and deterioration of their own health. Financial restrictions were also reported as a challenge.	11/20
Pesantes et al., 2017	Peru	N=12 (8 females, 4 males). Half were spouses and the other half were adult children. Ethnicity not stated however, four caregivers spoke Quechua as their native language and the remaining eight were immigrants from outside Lima. Mean age of the caregivers was 52.5 years. Almost all the caregivers (n=11) had been caregivers for over six months and only one was in this role for less than six months.	Qualitative >Semi-structured, in-depth interviews >Interview guide provided	All participants reported having experienced emotional stress and depressive symptoms because of caregiving. Reduced social activities and financial burdens increased caregivers stress. None of the caregivers had received training in post stroke care tasks. Almost all expressed the need to see a professional to improve their mental health	18/20
Pierce et al., 2007	USA	N=73 (55 females, 18 males). Over half were spouses, followed by adult children. The rest were other relatives or friends. 62 were White and the rest were African American, Hispanic and an American Indian. The mean age of the family caregivers was 55 years and they	Qualitative >Bi-weekly telephone interviews with open-ended questions for up to one year. >Interview guide topics provided	Family caregivers reported being frustrated in day to day situations particularly with providing physical tasks, household chores, and managing the emotions and behaviours of the stroke survivors. They also reported feeling inadequate and overwhelmed and seeking support from friends and family. Initially problems	12/20

		were providing care for up to one year.		centred on physical tasks and this shifted to dealing with dealing with behavioural and interpersonal issues.	
Saban and Hogan, 2012	USA	N=46 (all females, mainly spouses but sample also comprised of adult daughters and significant other.) Majority reported as White. Age range 18-73 (mean=56.2 years). Providing care within 3 months to 1 year.	Qualitative >Written questionnaire containing open-ended questions >Sample questions provided	Caregivers reported losing the life that once was in relation to the relationship with the stroke survivor; feeling overwhelmed with the demands of caregiving, missing personal time and facing an uncertain future. Financial strain and lack of support from friends and family; Lack of support from health care providers and dissatisfaction with health care provider care.	12/20
Secrest, 2000	USA	N=10 (8 females and 2 males). Eight were spouses and the other two were a parent and an adult child. Ethnicity not reported. Ages of participants ranged from 40-72. Duration since stroke ranged from 2-14 years.	Qualitative >In-depth interviews >Examples of questions on the interview guide provided	Challenges reported by family caregivers included difficulties managing the behaviour of the stroke survivor and this impacted on their relationship. They also reported vigilance and added responsibilities which contributed to physical and emotional strain.	16/20
Simeone et al., 2016	Italy	N=25 (20 females and 5 males). Twelve were adult children, 10 spouses and the remaining ones were siblings or other. Ethnicity not reported. Age between 38-74 years providing care for at least the first three months following hospital discharge.	Qualitative >Interviews with open-ended questions >Examples of questions utilised provided	Family caregivers reported a deeply changed life due to additional responsibilities and increased workload. They also reported lack of preparation in the caregiving role and difficulties in getting information and support from healthcare services.	18/20
Smith et al., 2004	UK	N=90 (65 females, 25 males). Relationship to the stroke survivors not stated. Ethnicity not stated. Aged between 19-84 years; mean age,	Qualitative >Semi-structured interviews	Family caregivers initially lacked skills to provide care; lacked knowledge to seek financial support; community support services did not always meet	18/20

		57.8 years. Caregivers providing care up to one year.	>Interview guide provided	their needs; changes in the stroke survivors' behaviour and personality affected their relationship with the caregivers. Adjusting to the caregiver role was a challenge for some participants due increasing workload, their age and deteriorating health	
Strudwick and Morris, 2010	UK	N=9 (8 females, 1 male, comprising of spouses, daughters and a niece). Ethnicity: African Caribbean, aged between 68-88 years, caring for at least 6 months	Qualitative >Semi-structured interviews >Interview guide provided	Lack of understanding of individual needs, battle to get support needed from services and lack of support from family members were the challenges highlighted by family caregivers.	16/20
Subgranon and Lund, 2000	USA	N=20 (13 females, 7 males; sample comprised of mostly adult children but also contained spouses and son/daughters in-laws). Ethnicity, all Thai. Age between 28-73 years. Caregivers providing care for a minimum of six weeks prior to the study.	Qualitative >Interviews, observations and researchers' memos >Sample questions or topics on the interview guide not provided	Family caregivers reported various challenges including tiredness, emotional distress, work overload and financial problems. Caregiving was seen s an unavoidable task due to religious beliefs. Family members were the major source of support for the family caregivers.	14/20
Torregosa, Sada and Perez, 2018	USA	N=8 (sample comprised of spouses, adult children, parents and or siblings). Ethnicity: Almost all were Mexican -Hispanic except for one who was Non-Hispanic White. Family caregivers' age ranged between 30-68 mean age 53.25. Stroke survivor's years of living with stroke ranged from 1 -24 years, mean 7 years.	Qualitative >Semi-structured interviews and a focus group discussion >Interview guide provided	Family caregivers reported emotional struggles and conflicting emotions as they felt ignored or neglected. They also reported constant worry due to lack of finances to support the needs of the stroke survivor as well as lack of knowledge regarding stroke. Establishing a balance between caregiving and still having a life of their own was a struggle for the family caregivers.	17/20

Van Dongen, Josephsson and Ekstam, 2014	Austria	N=3 (all female) Two spouses and an adult daughter. All Austrian aged between 49-59. Duration of caring ranged from three months to 14 months.	Qualitative >Semi-structured interviews >Interview questions provided	Family caregivers reported having less time for themselves, decreased enjoyment of their occupations. They also reported added responsibilities resulting in emotional strain. Employment was perceived as very important contributing to their well-being.	17/20
Wagachchige et al., 2018	Sri-Lanka	N=10 (8 females, 2 males). Sample comprised of spouses, adult children and one daughter-in-law. Ethnicity: All Sri Lankan, aged between 33-69 years, duration as caregiver between 1- 2.5 years.	Qualitative >In-depth interviews >Sample questions on the interview guide provided	Life alterations including physical and psychosocial aspects of their lives; lack of resources including finances, facilities at home to provide care and knowledge about stroke. Family caregivers reported providing compassionate care and neglecting their own needs. Self-encouragement and social networks were some of the coping strategies utilised by family caregivers.	17/20
Yeung et al., 2015	Canada	N=13 (6 females, 7 males). Sample comprised of adult children and spouses of the stroke survivor. All were Chinese. Age range 24 – 68; mean age 60. Caregivers providing care between two to 16 months.	Qualitative >Face to face or telephone qualitative interviews >Examples of questions on the interview guide provided	Family caregivers reported information and training needs to provide care to the stroke survivor stroke whilst others experienced problems communicating with healthcare professionals. Family caregivers discussed the need to have diverse resources across all care environments (acute and community).	14/20

Appendix 4: Summary of quantitative studies (n=15)

Glossary of Quantitative Tools	
Abbreviation	Full name
CAS	Carer Assessment Scale
CIRS	Cumulative Illness Rating Scale
CBS	Caregiving Burden Scale
CES-D	Centre for Epidemiologic Studies (20 items)
CESD-10	Centre for Epidemiologic Studies -10 item version
CIS	Caregiving Impact Scale
CIS-R	Clinical Interview Schedule - Revised
CRA	Caregiver's Reaction Assessment
CSI/CGSI	Caregiver strain Index
CSS	Carer Satisfaction Scale
GDS	Geriatric Depression Scale
GDS	Goldberg Depression Scale
GHQ-12	General Health Questionnaire

HADS	Hospital Anxiety and Depression Scale
HRQOL	Health-Related Quality of Life
IPSI	Interactional Problem-Solving Inventory
ISC	Instrumental Support Checklist
ISEL	Interpersonal Support Evaluation List
KOS	Knowledge of Stroke Scale
LiSat-9	Life Satisfaction Checklist
LSNS	Luben Social Network Scale
MLES	Modified Life Event Scale
MMSE	Mini-Mental Score Examination
OCBS	Oberst Caregiving Burden Scale
PACS	Positive Aspects of Caregiving Scale
POMS	Profile of Mood States Short Form
PSQI	Pittsburgh Sleep Quality Index
SCQ	Sense of Competence Questionnaire
SDS	Self-Rating Depression Scale
SF-36	Short-Form Health Survey (SF-36)

SPSI	Social problem-solving Inventory-Revised
SSL	Social Support List
SSS	Satisfaction with Stroke Services Scale
SSSI	Saranson Social Support Index
UCL	Utrecht Coping List
WHOQOL-BREF	World Health Organisation Quality of Life Instrument (26 items)

Appendix 4 (continued): Summary of quantitative studies

Authors / Year	Country	Participants details (relationship to stroke survivor, ethnicity, age and duration in caregiving role in months/ years	Methodology/ data collection	Key findings	QA (JBI)
Draper and Brocklehurst, 2007	UK	N=44 couples (All spouses, 31 female, 13 male). Age range 27-83 with a mean age of 65. Ethnicity not reported. Length of time since stroke ranged from 6 weeks to 15.5 months.	>Quantitative >Interviews >GHQ -12, CSI	Higher scores of GHQ-12 noted ranging from 4-30 with a mean value of 15.1 indicating a greater degree of psychological distress. Scores on the CSI ranged from 0 to 12 with a mode of 6. The items most frequently attracting a yes on the CSI were those asking whether caregiving was confining, whether caregiving had resulted in changes to personal plans and whether the stroke survivor had changed from his or her former self. Spouses supporting stroke survivors with speech problems experienced more strain.	14/16
Grant et al., 2006	USA	N=52 (46 female, 6 male). A majority were spouses (n=21) or daughters (n=18). The sample also included other family members related by blood or marriage. Age range from 25 to 74 years; mean age 55.6.	>Quantitative >Interviews >ISEL, SPSI-Revised, CES-D, SF-36	A decline in social support was linked to family caregivers' depressive symptomatology, well-being and general health. Higher levels of social support were associated with lower levels of caregiver	17/22

		Majority were white (n=37) but sample also included blacks. Data collected at 5,9, and 13 weeks following hospital discharge.		depressive symptomatology, and higher levels of well-being and general health.	
Haley et al., 2009	USA	N=75 (59 female, 16 male). Sample comprised of adult children, spouses and other family members. All participants were aged over 45; mean age 63.69. Ethnicity reported as White American (n=42) and Black American (n=33). Family caregivers were providing care between 8-12 months post- stroke.	Quantitative >Telephone interviews >Stressfulness rating instrument, Positive aspects of Caregiving Scale, CES-D scale, PACS, Caregiving strain question.	>56 % of family caregivers reported strain. The average CES-D score for caregivers was 7.32. The most stressful stroke-related patient problem as reported by family caregivers were mood disturbances of the stroke survivor.	13/16
Lurbe-Puerto, Leandro and Bauman, 2012	Luxembourg and Portugal	Two groups participated Group 1: N=62 patient-caregiver pairs (Luxembourg) Group 2: N=46 patient-caregiver pairs Portugal. Family caregivers in both samples were predominantly female (65.5% and 82.6%) respectively. The mean age for the Luxembourg sample was 59.3 and 60.7 for the Portugal sample. Majority of family caregivers in both samples were spouses of the stroke survivor; 82.3% in the Luxembourg sample and 60.9% in the Portuguese sample, however, the samples also included adult children and other relatives. Ethnicity as not stated. Interviews conducted at 2 years post-stroke.	Quantitative >Structured interviews >CRA, Life satisfaction, social and family repercussions, stroke-related repercussions on the couple relationship.	The experience of providing care differed in terms of family support and disruptions of the caregivers' family responsibilities. More Portuguese respondents gave activities up, found little time for relaxation and estimated that their health had deteriorated. Luxembourg caregivers felt strong enough to cope.	13/16

Mackenzie et al., 2007	UK	N=37 (69%, n=29 were females). The majority were spouses to the stroke survivor (n=24; 57%), the rest were either adult children/ in-laws or parents. The age range was 28 to 84 year, mean age; 61.7. Caregivers were predominantly from White ethnic group (78%) but sample also included caregivers from Asian and Black ethnic groups. Data was collected before discharge and again at 4-6 weeks post-hospital discharge.	>Quantitative >Survey >CAS, KOS, SCQ, SSS	>Following hospital discharge, problems identified by over half of the caregivers included fluctuation in mood, restriction to social life and getting tired. Dealing with psychosocial problems of fluctuation in mood and uncooperative behaviour were high priorities. >32% reported that they were not well prepared for going home. >Major information deficits concerned emotional and psychological problems, and handling stroke survivors changed behaviours.	16/22
Perry and Middleton, 2011	Australia	N=32 stroke patient -caregiver dyad (18 females and 14 males). The majority n=24 were spouses but sample also included adult children/in-laws and a parent. More than half were of White Australian origin with the remaining classified as other Asian. Interviews conducted within 1 and 3 months post-discharge from hospital.	Quantitative >Structured telephone interviews >CAS, KOS, SCQ, CSS	>Problems mentioned by the greatest number of caregivers included restricted social lives, tiredness distress at the stroke survivors state, the stroke survivors' mood fluctuations and difficulties getting information to prevent further stroke. >Highest overall levels of dissatisfaction were reported arising from non-receipt of information. Female caregivers reported and those interviewed later after discharge reported the greatest burden and needs; those with prior caregiving responsibilities reported greater needs and more negative consequences from the caregiving role.	15/22
Rittman et al., 2009	USA	N=276 (89.1% females; 70.1% spouses but sample also included a parent of the stroke survivor and other family members. Age range 18-88, mean age 60.7 years.	>Quantitative >Telephone survey >PSQI, CESD-10 scale, HRQOL	Most caregivers (88.7%) reported fair to excellent health. Sleep disturbance was reported in 80% of participants. Depression scores were higher for caregivers getting 1 to 5 hours of sleep compared with those getting	13/16

		More than half of the sample (59%) were non-Hispanic white but sample also included African Americans, Latinos and other races. Duration in caregiving role ranged from 9 months to 6.7 years.		6 or more hours of sleep. Caregiver burden was higher for caregivers who wake at night to care for the stroke survivor (12.08) compared with those who do not wake (7.67) and those who wake for other reasons (8.49).	
Simon, Kumar and Kenrick, 2008	UK	T1 - prior to hospital discharge T2- 6 weeks post-discharge N=74; 54 female, 20 male; Age range 22-91, median age 66.8. T3- 15 months post-discharge N=53; 39 female, 14 male; Age range 32-88, median age 65.6. All participants were Caucasian except two.	>Quantitative >Structured interviews > CIS-R, self-rated physical health, social well-being, SSSI, activity restriction, the presence of other commitments or previous caregiving experience.	At T2 significant reduction in psychological health noted between pre-discharge and early post-discharge interviews (CIS-R score 11.5 versus 13.6). Significant deterioration in relationship quality between the caregiver and stroke survivor noted from T1. At T3, no further reduction in psychological health, self-rated health and relationship between stroke survivor and caregiver noted. However, 20 family caregivers still had significant distress. 90% (N=18) of those distressed at T3 were distressed at T2. Significant reduction in both reported quantity and quality of informal social support between pre-discharge and T3. Furthermore, the number of formal support services decreased significantly between T2 and T3 (5.5 versus 4.1 respectively).	16/22
Singh and Cameron, 2005	Canada	N=48 (36 female, 12 male). Over half (n=31) were spouses of the stroke survivor whilst the rest were other relations. Age range 25 to 88 years; mean age 54.58 years. Ethnicity not reported. Only seven family caregivers had previous caregiving experience whilst the rest did not. About half combined caregiving and	Quantitative >Telephone or face to face structured interviews > CIS, Bother scale, CSS, Perlin's 7-item measure, Caregiver self-efficacy scale, SSSI, ISC, POMS	The higher the amount of caregiver burden, the greater the lifestyle impact and emotional distress for the caregiver. Caregiver satisfaction was not found to be associated with emotional well-being. However, the caregivers' sense of mastery was found to moderate the relationship between lifestyle impact and emotional wellbeing.	12/16

		employment. Family caregivers were providing care in the home for a minimum of one-month post-hospital discharge. The average length of caregiving in the home was 20.8 months with one caregiver providing care for 17 years.			
Ski and O'Connell, 2007	Australia	N=13 (7 male, 6 female). 10 spouses, three siblings of the stroke survivor. Age range 42-81, mean age 66.23. Ethnicity of participants not stated. Interviews conducted at T1 (3 weeks post-discharge) and T2 (3 months post-discharge).	>Quantitative (part of a larger project) >Structured interviews >WHOQOL-BREF, SDS	Family caregiver scores demonstrated a lower quality of life and higher depression than population norms at 3 weeks and 3 months post-hospital discharge. No significant changes were noted on caregivers' general well-being. >Varying levels of support were reported by the family caregivers. Although all family caregivers received information, six (55%), reported that the information was inadequate. Furthermore, most caregivers (N=8; 62%) stated that they felt let down professionals because they found out about community services by themselves through friends, the internet or other family caregivers.	14/22
Smith-Johnson et al., 2015	USA	N=38 (All participants were female). The majority were spouses n=20. The sample also included adult children and other relatives. Age was recorded as below 65 (n=23); above 65 (n=15). All participants self-reported as being African American. Caregivers had been providing care between 1 and 2 years.	>Quantitative >Not clearly stated how data was collected. >Perlin's Caregiving and Stress Process Tool (Adapted version) was used to identify stressful situations	More family caregivers responded yes to stressors associated with assisting survivors with activities of daily living. Family caregivers reported being forced into the caregiving role; many were not prepared and experienced much stress related to the lack of knowledge, training and minimum assistance from other family members.	9/16

Steiner et al., 2008	USA	N=73 (75% were female). The majority were spouses of the stroke survivor, but the sample also included adult children and friends. Age range 23 – 79; mean age 55 years. Participants were predominantly white (85%) but sample also included Black and Hispanic and American Indian caregivers. Data collection at baseline, 3, 6 and 12 months post-stroke.	>Quantitative (part of a larger project) >Structured telephone interviews >Emotional support >Physical help >Caregiver health	Family caregivers' health ratings were stable throughout all time periods, however, over the 12 months period, caregivers reported having received a lot of emotional support from friends and family. >Significant moderately positive relationships between emotional support and caregiver health were also noted at 6 and 12 months ($p<.05$). >No significant relationship between physical help and caregiver health at any time. However, significant moderately positive relationships between emotional support and caregiver health were noted at 6 and 12 months ($p <.05$). A positive association between emotional support and caregiver health.	15/22
Tang et al., 2011	Hong Kong	N=123 (The majority were female n=89; 34 males). Mean age of participants was 61.4. Relationship with stroke survivor described as adult family member. Ethnicity was not stated; however, participants were described as Hong Kong residents of Chinese descent. The mean duration as a caregiver was 6.3 months.	>Quantitative >Structured interviews >GDS, CBS, HADS, MLES, CIRS, MMSE, LSNS, general fatigue	Family caregivers' severity of depressive symptoms was significantly related to their burden on the CBS. Family caregivers' poor self-rated general health was noted to be a significant contributor to the severity of their depressive symptom.	11/16
Visser-Miely et al., 2008	Netherlands	N=119 (All were spouses of the stroke survivor; 65% female). Age range 24-77; mean age 55 years. Ethnicity not stated, however, all participants spoke Dutch. Interviewed at 1 year and 3 years post-stroke.	Quantitative >Structured interviews >CSI, LiSat-9, GDS, IPSI, SSL, UCL	51% of spouses reported significant strain (CSI >7); 46% were dissatisfied with life (total LiSat-9 <4) and 51% reported depressive symptoms (GDS >2) at 1 year after stroke. Burden scores at 3 years diminished significantly with the percentage of spouses reporting significant strain decreasing from	17/22

				51% to 44%. The other scores in psychosocial functioning were substantially worse at 3 years compared to 1-year post-stroke.	
Visser- Miely et al., 2009	Netherlands	N=211 (all spouses of the stroke survivor; 61% female). Mean age 54; family with children under 18 (28%). Ethnicity not stated, however, participants spoke Dutch. Burden measured at T2- 2months, T-3 (1 year) and T-4 (3 years) post-stroke.	>Quantitative >Structured interviews >CSI, GDS, IPSI, SSL, UCL	Caregiver burden decreased significantly between T2, T3 and T4. No significant changes in the percentage of family caregivers with depressive symptoms between T2, T3 and T4 with many caregivers (50%) still reporting depressive symptoms. Social relations showed no change between T1 and T2 but decreased between T2, T3 and T4. Coping was most strongly associated with the course of psychosocial functioning; using a passive coping strategy as generally associated with negative outcomes whereas using active coping strategies was and seeking social support was associated with positive outcomes.	17/22

Appendix 5: Search strategy tools literature

Strategy 594829

#	Database	Search term	Results
1	AMED	(stroke OR "cerebrovascular accident").ti,ab	8452
2	AMED	(care* OR caregiver* OR famil OR spouse).ti,ab	37513
3	AMED	(1 AND 2)	1286
4	AMED	(burden OR strain OR needs).ti,ab	12107
5	AMED	("assessment tool" OR scale* OR questionnaire* OR measur*).ti,ab	62099
6	AMED	(4 AND 5)	3437
7	AMED	(3 AND 6)	89
8	AMED	7 [DT 2017-2019] [Languages English]	0
9	BNI	(stroke OR "cerebrovascular accident").ti,ab	8642
10	BNI	(care* OR caregiver* OR famil OR spouse).ti,ab	244184
11	BNI	(9 AND 10)	2631
12	BNI	(burden OR strain OR needs).ti,ab	52052
13	BNI	("assessment tool" OR scale* OR questionnaire* OR measur*).ti,ab	98171
14	BNI	(12 AND 13)	9558
15	BNI	(11 AND 14)	130
16	BNI	15 [DT 2017-2019]	21

17	CINAHL	(stroke OR "cerebrovascular accident").ti,ab	75938
18	CINAHL	(care* OR caregiver* OR famil OR spouse).ti,ab	767682
19	CINAHL	(17 AND 18)	11399
20	CINAHL	(burden OR strain OR needs).ti,ab	392558
21	CINAHL	("assessment tool" OR scale* OR questionnaire* OR measur*).ti,ab	773964
22	CINAHL	(20 AND 21)	102295
23	CINAHL	(19 AND 22)	921
24	CINAHL	23 [DT 2017-2019] [Languages eng]	158
25	Medline	(stroke OR "cerebrovascular accident").ti,ab	214250
26	Medline	(care* OR caregiver* OR famil OR spouse).ti,ab	1455464
27	Medline	(25 AND 26)	22894
28	Medline	(burden OR strain OR needs).ti,ab	831948
29	Medline	("assessment tool" OR scale* OR questionnaire* OR measur*).ti,ab	3570097
30	Medline	(28 AND 29)	154762
31	Medline	(27 AND 30)	948
32	Medline	31 [DT 2017-2019] [Languages English]	194
33	PsycINFO	(stroke OR "cerebrovascular accident").ti,ab	30563
34	PsycINFO	(care* OR caregiver* OR famil OR spouse).ti,ab	434629

35	PsycINFO	(33 AND 34)	4195

Appendix 6: Summary review table - quantitative studies (tools for assessing stroke family caregivers)

Glossary of quantitative tools on the last page of Appendix 6.

Author, year and country	**Study focus**	**Participant details/ Sample**	**Methodology/ data collection**	**Tool used and timing of assessment**	**Key Findings / Comments** *(indicator of quality from the JBI tool appropriate for study type)*
Bakas and Champion 1999, USA	Development and psychometric testing of the Bakas Caregiving Outcomes Scale	N=92 family caregivers sample 1 N=104 family caregivers sample 2 >Caregivers' demographics provided in both samples. 64.7% of caregivers were women. Ethnicity reported. 80% of caregivers living with stroke survivors. Caregiver definition provided. >Patient characteristics reported in relation to patient disability i.e. difficulty speaking, disorientation >CSS	>Quantitative >Self-mailed questionnaires (sample 1) >Structured interviews (sample 2) >BCOS, ACS, SF-36, LIFE-3, POMS	>BCOS >Timing of assessment Variable. Mean time since stroke was 17.7 months	> 48 items for the BCOS generated from the literature; 27 judged as content valid by five experts - all professionals. >Item analysis in sample 1 yielded 12-item BCOS and in sample 2 yielded 10-item BCOS. >Sample 1: 12 item scale alpha =.90. Sample 2: 10 item scale alpha =.77. (12/16)

Blake and Lincoln, 2000, UK	To identify factors associated with caregiver strain following stroke	N=222 spouses >Caregivers Approximately 66% of caregivers were women in both samples. Ethnicity and definition of caregiver not reported. Living arrangements reported as co-resident spouses. >Patient characteristics EADL London Handicap Scale GHQ-12	>Quantitative > Postal survey >CSI, PSS, GHQ-12, PANAS, CECS, LOT, SWLS	>CSI >PSS Variable- not specified	>37% scored seven or above on the CSI indicating significant strain. >Strain was highly correlated with negative affectivity on the PANAS, caregiver mood on the GHQ-12 and caregiver perceptions of patient's independence in activities of daily living on the EADL. (12/16)
Blake, Lincoln and Clarke, 2003, UK	To test the ability of a previously generated logistic model to predict caregiver strain from carer mood, negative affectivity and perceived patient function	N=116 spouses >Caregivers Only age and gender reported. Ethnicity not reported. 72% of caregivers were women. Living arrangements reported as co-resident spouses. >Patient characteristics	>Quantitative >Prospective postal survey > CSI, GHQ-12, PANAS	>CSI 3 months and 6 months post-stroke	>34% were under significant stress at three months and 35% at six months respectively. >The predictive model using the GHQ-12, PANAS and EADL at 3 months was 78% accurate in predicting levels of caregiver strain at six months. (12/16)

		EADL			
Caro et al., 2018, Brazil	To investigate the correlation between burden, quality of life and other variables such as physical, social, psychological, environmental and the care period.	N=30 caregivers >Caregivers Demographic information provided. Ethnicity not reported. Living arrangements stated. > Patient Cognitive impairment and walking dependence reported as stated by the caregivers.	>Quantitative >Correlational cross-section study > Face to face Interviews >ZBIS, WHOQOL-BREF	> ZBIS Approximately one-year post stroke	>The average burden score on the ZBIS was 29.6 representing moderate burden score. >Significant weak negative correlation was observed between burden and environmental domains. Caregivers presented with moderate levels of burden and reduction in quality of life. >Levels of burden correlated negatively with environmental domains, quality of life and physical domains; however, these correlations were weak indicating possible interference with other factors. (13/16)
Choi-Kwon et al., 2005, South Korea	To investigate factors affecting the burden on caregivers of stroke survivors in South Korea	N=147 caregivers > Caregivers Demographic information provided as well as information about the presence of an alternative caregiver and hours of caring per day. Caregiver definition provided. Ethnicity not reported.	>Quantitative >Cross-sectional study > Structured interviews >SCQ, Global health item, HADS,	>SCQ Variable: 1 to 5 years; average 3.4 years after stroke onset	>Patient factors related to burden were being unemployed, presence of diabetes, aphasia, dysarthria, dysphagia, cognitive dysfunction, severe MRS score. >Caregiver factors related to high burden were being female, unemployment, being daughter-in-law, long caring hours and psychological problems. (14/16)

		> Patient characteristics MRS, MMSE, demographic data, presence of risk factors, motor impairment, sensory symptoms, aphasia, dysarthria, dysphagia, and recurrent stroke.			
Choi-Kwon et al., 2009, USA and Korea	Comparing Perceived Burden for Korean and American Informal caregivers of Stroke Survivors	N=74 (USA-33; Korea -41) >Caregivers Demographic information including the number of hours spent caring reported. Majority of caregivers at both sites were women. Caregiver definition, living arrangements and ethnicity reported. > Patient characteristics BI, DISH	>Quantitative >Descriptive comparative study. > Structured interviews > SCQ, HADS, GDS	>SCQ (Variable) >USA - 4 months post stroke onset. >Korea - 14 months post stroke onset.	>The overall burden scores were significantly higher in the Korean cohort than in the American cohort. Tool validity for this sample not given. >Korean caregiver groups had significantly higher burden scores in the subscale regarding satisfaction with relationship with the recipient of care than did the Seattle group. (13/16)
Chuluunbaatar et al., 2017, Mongolia	To determine the changes in caregiver burden	N=103 > Caregivers	>Quantitative >Observational prospective study	>Modified Montgomery CGB scale	>A paired t-test analysis revealed that demand burden increased whereas stress burden decreased.

	between acute stages and one year after stroke and identify associated factors with changes in caregiver burden	Demographic information including co-habitation status and caregiver definition provided. Majority were female. > Patient characteristics BI, MRS, GCS	>Structured interviews > Modified Montgomery CGB scale	Ten days since stroke onset and 1 year after first interviews	>Factors associated with these changes were caregiver's marital status, the caregiver's relationship with the patient, financial difficulties, patients' sex and dependency. (18/22)
Das et al., 2010, India	To assess caregiver burden among stroke caregivers in Kolkata, India.	N=199 patient and caregiver dyads >Caregivers Demographic information including co-habitation status with the patient reported except ethnicity. Majority were women. Caregiver definition provided. >Patient characteristics BI, MSE, GDS, Everyday Abilities Scale for India	>Quantitative >Cross-sectional study >Structure interviews >BAS	>BAS Variable- not specified	>More than 80 % of caregivers reported financial worry, 70% increased workload, 76% related anxiety and depression and 43% sleep disturbance. >Caregivers of patients with dementia and depression experienced greater stress. >Issues of sexuality were excluded in the BAS assessment questionnaire as both field workers and respondents were reluctant to address it thus this does not give full overview of the BAS tool in this study. (14/18)
Denno et al., 2013, USA	To investigate the relationship	N=153 caregivers	>Quantitative	> BCOS >OCBS	>OCBS-Difficulty score was a statistically significant predictor of

	between anxiety and depression and caregiver burden in informal caregivers of stroke survivors with spasticity.	>Caregivers Demographic information reported including ethnicity. Majority were women. Family caregivers' living arrangements not clearly described. Caregiver definition not provided. >Patient characteristics BI	>Cross-sectional online survey >BCOS, OCBS, PHQ-9	Variable providing care at least 6 months)	anxiety, depression. As caregiver burden increases, caregivers are more likely to have anxiety and depression. >BCOS (15 item scale) Cronbach alpha o0.944 indicating high reliability. >OCBS Time and Difficulty subscales had Cronbach alpha values of .913 and .938 respectively, also indicating high reliability. (12/16)
Elmstahl, Malmberg and Annerstedt.,1996 Sweden	To assess burden of caregivers to stroke patients 3 years after stroke and to test validity and reliability of the CB scale	N=35 >Caregivers Minimal caregiver demographics reported i.e. type of relationship and gender; However, time spent weekly with patient and usage of home help services reported. Ethnicity and living arrangements of caregivers not reported. Definition of caregiver provided.	>Quantitative >Structured interviews >CB scale, CPRS	>CB scale (3 years post stroke)	>CB scale had Cronbach alpha value of .70 to .87. >A higher burden was related to a closer relationship but not to the living situation. The highest caregiver burden was found among patients showing the greatest improvements of ADL. >Validation of the CB scale tested in caregivers of 67 stroke patients and 83 patients with dementia. (18/22)

		>Patient characteristics KIADL, EPI, LGC			
Evans, 1986 USA	To investigate the relationship between burden of home care on the primary caregiver and their ability to comply with a permanent regimen of therapy on behalf of the stroke survivor	N=52 >Caregivers Minimal caregiver demographic information reported i.e. only age, gender and ethnicity. Majority were women. Caregiver definition not provided. Caregiver living arrangements in relation to the stroke survivor not reported. >Patient characteristics Reported as most requiring wheelchair for mobility and dependent in self-care.	>Quantitative >Correlation study >Structured interviews >ZBI, Adherence Rating Scale	> ZBI (1-year post discharge)	>Family caregivers who comply with expectation for rehabilitation may tend to experience an increase in the sense of burden. >Pearson correlation of .23 ($p > 0.5$) was obtained on the burden scale and on the adherence ratings. (10/16)
Han et al., 2017, China	To describe determinants of caregiver burden within the first six months	N=164 patient and caregiver dyads >Caregivers	>Quantitative >Prospective longitudinal study. > Face to face interviews >CSI, CES-D, MSPSS	>CSI	>Family caregivers reported higher mean burden at T1 but decreased over time at T4. Caregivers had moderate mean social support throughout the six months period.

		Demographic information provided including cohabiting status with the patient. Ethnicity not reported. Majority were female. >Patient characteristics BI, SPMSQ,		T1 =1-2 days before hospital discharge T2 =3 weeks post hospital discharge T3 = 3 months post hospital discharge T4 = 6 months post hospital discharge	>Determinants of caregiving burden were stroke survivor's physical dependence, caregivers' age, caring hours per day, depressive symptoms and social support. (18/22)
Isaac, Stewart and Krishnamoorthy, 2011, India	To investigate the associations between caregiver burden and stroke survivors' quality of life.	N=46 patient and caregiver dyads >Caregivers Demographic information reported except ethnicity. Majority female. Caregiver definition or living arrangements not reported. >Patient characteristics BI, HAM-D, WHOQOL-Bref	>Quantitative >Cross-section study >Structured interviews >ZBI	>ZBI Variable- at least six months since stroke.	>54.3% of family caregivers experienced considerable burden. The level of caregiver burden was a significant correlate of quality of life after controlling for patient depression, disability and economic dissatisfaction. >Patient economic dissatisfaction, patient depression and caregiver burden were independently associated with lower patient quality of life. (12/16)

Jaracz et al., 2012, Poland	To analyse predictive factors of the overall burden in caregivers of stroke survivors and to verify structural model of burden, built on the basis of theoretical and empirical assumptions	N=150 patient and caregiver pairs >Caregivers Demographic information reported except ethnicity. Caregiver living arrangements reported. Caregiver definition not provided. Majority female. >Patient characteristics BI, SSS, GDS	>Quantitative >Descriptive correlation study >Structured interviews >CB scale, SOC-29, BSSS, HADS-A, HADS-D	>CB scale (Polish version) six months post hospital discharge	>Family caregivers experienced a moderate burden (mean CB=2.08) and emotional distress (mean total HADS =14.1). >Analysis showed that higher burden was associated with lower SOC score, higher emotional distress and lower patient's functional status. Results indicate that burden and degree of emotional disturbance are two distinct negative consequences of caregiving. (18/22)
Jaracz et al., 2014, Poland	To evaluate severity of burden experienced by caregivers and to identify the best predictors of caregivers from the characteristics of patient and characteristics of caregivers	N=150 patient/caregiver pairs >Caregivers Demographic information reported including living arrangements. Caregiver definition provided. Majority female. All participants reported as Polish.	>Quantitative > Prospective cross-sectional study. >Structured interviews >CB scale, SOC-29, BSSS, HADS-A, HADS-D	Caregiver Burden Scale (CB scale) (six months after discharge)	>47% of caregivers reported a substantial burden. >Family caregiver sense of coherence, anxiety and patient's functional status were the most important predictors of the overall burden and the most consistent predictors of the majority of the aspects included in the CB scale. (18/22)

		>Patient characteristics BI, SSS, GDS, Dynamic Assessment of Aphasia Scale.			
Jaracz et al., 2015 Poland	To assess prevalence and determinants of burden in caregivers of long-term stroke survivors five years after stroke	N=88 patient/caregiver pairs >Caregivers Demographic information reported including living arrangements and time spent caring per day. Ethnicity not reported. Caregiver definition not provided. >Patient characteristics BI, SSS, GDS,	>Quantitative ->Non-experimental descriptive study >Structured interviews >CB scale, HADS-D, HADS-A, BSSS, WHOQOL-Bref, SOC	>CB scale T1- 6 months post discharge T2 -5 years post discharge	>Considerable burden was reported by 44 % of caregivers at T1 and 30% at T2. >Burden was independently associated with caregivers' sense of coherence and amount of time spent caregiving at T1 and with caregivers' anxiety at T2. (19/22)
Kamel, Bond and Froelicher, 2012 Jordan	To investigate the relationship between patients' characteristics, duration of caregiving, caregiver	N=116 >Caregivers Caregiver demographics reported including living arrangements	>Quantitative >Cross sectional design >Structured interviews >CSI, CESD	>CSI Variable (3 months to 8 years)	>Caregivers had high scores for depression and burden indices. >Caregivers' health, receiving professional home health care and caregivers' burden were related to caregiver depression. Functional

	characteristics, caregiver depression and burden in caregivers of patients with stroke.	and duration of caregiving. Ethnicity reported. Majority female. Caregiver definition not provided. >Patient characteristics BI, MMSE,			disabilities of patients with stroke and depression of caregivers were related to caregiver burden. (13/16)
King et al., 2013, USA	Development and Psychometric testing of the Stroke Caregiver Unmet Resource Needs Scale (URNS)	N=166 >Caregivers Caregiver definition provided. >Patient characteristics FIM	>Quantitative >Longitudinal, exploratory study >Face to face and telephone interviews >URNS, CES-D, ACS-Revised, PPO, IEQ, PCS	>URNS T1 - baseline acute rehabilitation T2 - 3 to 4 months post-discharge T3 - 6 months post discharge T4 - 12 months post discharge	>Tool items generated from findings of earlier studies. > Structure of instrument assessed using principal axis factoring (PAF) and Promax rotation at T3. > PAF was computed on T3 13 item scale with no missing data. >Cronbach alpha were over .70 for the total scale and general needs subscale at all times in the sample of 166 caregivers. >Each item was endorsed as unmet by a minimum of 12% of caregivers. Items endorsed as a need by 20% or more were: needed a service to help with caregiving but did not have it; needed services for my emotional needs but was reluctant to use them; I did not know what kind of resources would help; I did not know where to get help finding resources. >Unmet needs remained common at one year when 42% of 123 caregivers

					reported one or more unmet resource needs. (19/22)
Lee and Mok, 2011, China	To develop and test psychometric properties of the modified Chinese version of the Caregiver Task Inventory (CTI-25)	Phase 1- n=6 experts (5 professionals and one caregiver) Phase 2 –n=144 > Caregivers Demographic information including living arrangements reported. All participants reported as Chinese. Caregiver definition given >Patient characteristics Stroke survivors described as elderly stroke patients.	>Quantitative >Phase 1- developing CTI-25. Panel of six experts rated the original CTI-45 independently for relevance and repetition of content using the content validity index (CVI). >Phase 2 – Questionnaire self-completed by caregivers (15-20 min)	>CCTI (variable providing care at least for 6 months or more)	> All items on the CTI-25 were found to have acceptable CVI between 0.60 -0.75 as well as semantic equivalence above 75% appropriateness >The internal consistency and stability of the CTI-25 was 0.93 and the internal reliability (item-total correlation) for five refined sub-scales ranged from 0.67-0.86. (13/16).
Mackenzie, Holroyd and Lui, 1998, China	To identify appropriate assessment procedures for ascertaining the needs of family caregivers and pilot a scale for inclusion	Phase 1- N=13 community nurses Phase 2- N=14 caregivers; 13 community nurses > Caregivers	Mixed methods design Phase 1 -Qualitative >Semi-structured interviews with 13 community nurses >Observation of eight community nurses	>CAS Variable- not specified	>The CAS was able to identify areas of need of Hong Kong family carers looking after stroke patients. >The CAS seem to be feasible if incorporated into the overall assessment of the family and patient. The scale was not tested for reliability in this study. (14/16)

	assessment of family caregivers.	Minimal caregiver demographic information reported- only their relationship to the stroke survivor and living arrangements reported. Ethnicity not reported. Caregiver description/definition provided. >Patient characteristics Stroke survivors described as 'dependent' family member being visited by community nurses.	>Examination of records of patients visited Phase 2 – Quantitative >Piloting the CAS with caregivers and community nurses. CAS self-completed by caregivers.		
Mackenzie et al., 2007 UK	To identify the needs of family caregivers before discharge and 4-6 weeks after discharge.	N=42 caregivers >Caregivers Demographic Information including living arrangements, ethnicity and their existing medical conditions were reported. Definition of caregiver provided.	>Quantitative > Face to face survey of needs >CAS, KOS, SCQ, SSS	>SCQ >CAS	>Internal consistency for the SCQ was 0.90. >Wide ranging problems covering physical, social, and emotional aspects of caring were identified using the CAS and continued to be problems at 4-6 weeks after discharge. (14/18)

		>Patient characteristics BI			
Macnamara et al., 1990, USA	To characterise caregiver strain in a sample of successful stroke-patient caregivers.	N=41 caregivers >Caregivers Demographic information and living arrangements reported. Ethnicity not reported. Majority female. >Patient characteristics BI	>Quantitative >Face to face structured interview >CSI, POMS	>CSI Variable - mean months post-stroke at the time of interview was 14.63 with a standard deviation of 8.78.	>Caregiver reported a moderate level of stress as indexed by the CSI. > The correlation values of the CSI with POMS anxiety, depression and hostility scales were .57, .59 and .66 respectively. >Caregivers anxiety increased with the passage of time despite not seeking any help. (14/16)
McKenna et al., 2013, UK	Exploration of caregiver experience and level of burden after decompressive hemicraniotomy following malignant middle cerebral artery infarction	N=6 >Caregivers Minimal caregiver demographic details provided. Caregiver ethnicity and living arrangements not reported. Caregiver definition not provided. >Patient characteristics Those with malignant MCA	>Mixed methods study >Quantitative: self-completed questionnaires >SCQ and HADS	>SCQ Variable - Assessments done at variable times within preceding 10 years.	>While caregivers experienced many losses, their overall sense of burden was not outside average limits nor did they experience clinically significant symptoms of depression. All caregivers identified methods of coping with demands of caregiving. (15/18).

		infarct who had undergone decompressive hemicraniotomy			
Morais et al., 2012, Brazil	To analyse the impact of caring for patients after stroke, correlating life changes and psychological distress with perceived overload	N=61 >Caregivers Demographic information reported, however, ethnicity and living arrangements not reported. Caregiver definition not reported. Clinical profile of caregivers reported i.e. their own illnesses. Majority female >Patient characteristics Stroke survivors' characteristics not reported.	>Quantitative >Cross-sectional study >Structured interviews >CB scale, MMSE, SRQ	Caregiver Burden Scale (CB scale) Variable - at least providing care for 2 months; average 9 months.	> Regarding burden, the dimensions of general tension, isolation and disappointment stood out. Burden was more severe in caregivers with psychological distress, caregivers without a secondary caregiver and when caregivers reported changes with their health. >The most cited life modifications referred to the daily routine, leisure activities, and to exhaustion or tiredness. (15/16)
Morimoto, Schreiner and Asano, 2003, Japan	To examine the relationship between caregiver burden and health-related quality of life in family caregivers of older stroke	N=100 >Caregivers Demographic information reported including living arrangements, average daily hours of caregiving and	>Quantitative >Descriptive non-experimental study >Interviews >ZBI, GDS- Short form SF-12 Health Survey,	ZBI Variable	>Increased caregiver burden was significantly related to worsening health-related quality of life, particularly worsening mental health even after controlling for caregiver age, sex, chronic illness, average caregiving hours/day, and functional dependence of the care-recipient.

	patients and to examine the characteristics of the caregiving situation that significantly relate to increased burden	availability of a respite caregiver. Majority female. Ethnicity not reported. Caregiver definition provided. >Patient characteristics MBI			>Neither duration of caregiving, degree of patient functional dependency, caregiver chronic illness, nor presence of a respite caregiver related to the degree of caregiver burden; however increased caregiving hours significantly related to caregiver burden. (15/16)
Olivia-Moreno et al., 2018, Spain	To investigate burden and the risk of caregiver burnout at 3 and 12 months after stroke	N=224 caregivers at 3 months N=202 caregivers at 12 months >Caregivers Caregiver demographics provided including number of caregiving hours and task. Ethnicity and living arrangements not reported >Patient characteristics BI, NIHSS, EuroQol-5D presence of Atrial fibrillation (AF).	>Quantitative >Prospective observational study >Structured interviews > ZBI	>ZBI T1- before hospital discharge T2- 3 months post-discharge T3- 12 months post-discharge	>80% of those still alive were receiving informal care at 3 and 12months post stroke. >More than 40% of those receiving care needed a secondary caregiver at 3 months post stroke. >When informal care was provided both the burden borne by caregivers and burnout were associated with caregiving hours; the patients' health-related quality of life, severity of stroke at discharge, degree of dependence and patient having AF. (18/22)

Op Reimer et al., 1998a, Netherlands	To evaluate the reliability and validity of the SCQ in a population of partners of stroke patients	N=166 Group A N=47 Group B >Caregivers Minimal caregiver demographics reported i.e. age, gender and living arrangements. Ethnicity not reported. Caregiver definition not reported. Majority of caregivers were female. >Patient characteristics MMSE, BI, MRS, SIP	>Quantitative >Part of multicentre study >Self-report questionnaires and structured telephone interviews >SCQ	>SCQ Group A- six months post stroke. Group B- variable times post stroke (range 3-24 months) for the test-retest reliability.	>The reliability of the total SCQ was good Cronbach alpha 0.83; interclass correlation coefficient =0.93 >Clinical validity was supported by the association between higher SCQ burden scores and patient's impaired functional health: cognitive function, disability, handicap and quality of life. >Feasibility of SCQ -the mean time to complete SCQ by a trained research assistant during a telephone interview- less than 10 minutes; the stroke partners needed 15-20 minutes to complete the SCQ. Additionally, both samples i.e. Group A and B had less than 10% missing scores. (14/16)
Op Reimer et al., 1998b, Netherlands	To describe the level and specific nature of burden of caring as experienced by caregivers of stroke survivors and to estimate the relative contribution of patient and partner characteristics to	N=115 partners of stroke survivors >Caregivers Demographic information reported except ethnicity. Majority were female. Caregiver definition not provided. Caregiver living arrangements not reported.	>Quantitative >Descriptive study as part of a multicentre study. >Self-report questionnaire >SCQ, Loneliness questionnaire	>SCQ (3 years post stroke)	>Partners of stroke patients perceived most caregiving burden in terms of feelings of heavy responsibility, uncertainty about patients care needs, constant worries, restraints in social life, and feelings that patients rely on only their care. >Multiple regression analysis revealed that a higher level of burden could partly be explained by patient's disability but primarily by partners'

	the presence of burden	>Patient characteristics GCS, BI, MRS, FAI, Stroke type			characteristics in terms of emotional distress. (12/16)
Ostwald et al., 2009, USA	To describe levels of stress using the perceived stress scale in stroke survivors and spousal caregivers at different time points and to identify predictors of stress among stroke survivors and their spousal caregivers	N=159 stroke survivor and caregiver pairs (spouses or committed partners) >Caregivers Demographic information provided including ethnicity and living arrangements. Majority female. >Patient characteristics FIM, SIS, Self - Rated Health Status, PSS	>Quantitative >Longitudinal study >Structured interviews >PSS, MOS, Self-Rated Health Status Scale, F-COPES, PCS	PSS T1- at discharge, T2- 3 months post discharge T3- 6 months post discharge T4-12 months post discharge	>PSS scores for stroke survivors and caregivers were positively correlated. Scores decreased significantly over the year but caregivers had higher scores initially. Stroke survivor function was a significant predictor of stress for both survivor and caregivers. >Cronbach alpha coefficient for PSS in this study was 0.85. (17/22)
Othman and Teck., 2014, Malaysia	Validation of Malay Caregiver Strain Index	N=50 >Caregivers Demographic information including ethnicity and living arrangements reported. Majority female. Caregiver	>Quantitative >Validation study >Structured interviews	CSI-M Variable	>The CSI-M has a good face and content validity. >Internal consistency Cronbach alpha of CSI-M in this study is 0.79. (12/16)

		definition not provided. >Patient characteristics Elderly stroke patients (over age 60)			
Pendergrass et al., 2015, Germany	Tool development and validation - An abbreviated German version of the Sense of Competence Questionnaire among family caregivers of stroke survivors.	N=122 baseline data of RCT N=76 survey data (n=198 total) >Caregivers Caregiver demographic including ethnicity reported. However, caregiver definition and caregiver living arrangements not reported. Majority of caregivers female. Patient characteristics Stroke survivor aged 60 and over, EBI	>Quantitative >Baseline data from RCT and survey data >Face to face or telephone structured interviews >SCQ, CES-D, CSI	>Abbreviated German SCQ Variable - providing care for a minimum of 6 months	>The abbreviated German SCQ Cronbach alpha 0.89 for the entire scale in this study. >All items have item-subscale correlations above 0.30. demonstrating good homogeneity. The internal consistency assessed by item-item correlations showed that there was no item redundancy. (13/16)
Perry and Middleton, 2011, Australia	An investigation of family carers needs following	N=32 patient/caregiver dyads	>Quantitative > Descriptive non-experimental study.	>SCQ >CAS	>Female caregivers, those with prior caregiving responsibility and those interviewed at 3 compared to 1-month

	stroke survivors discharge from acute hospital care in Australia	>Caregivers Caregiver and patient demographic details provided. Majority of caregivers were female. Caregiver ethnicity reported. Caregiver definition and living conditions not reported. >Patient characteristics mBI	>Record audit and structured interviews >SCQ, CAS, KOS, CSS	1 and 3 months after discharge	post-discharge reported greatest needs and burden from the caregiving role. >Needs alone significantly predicted burden. Internal consistency of CAS items in this study 0.85. (16/22)
Pfeiffer et al., 2014, Germany	Intervention study for caregivers experiencing significant strain in their role.	N=122 caregivers (intervention n=60, control n=62). >Caregivers Caregiver demographics reported including ethnicity; 82% native Germans. 77% of caregivers' women. Caregiver definition not provided. Caregiver living arrangements not reported	>Quantitative >Randomised control trial >Problem-solving intervention comprised of 2 home visits and 18 phone calls >Questionnaire and structured interviews >SCQ, CES-D, SPSI, GBB-24	SCQ Variable (minimum 6 months up to five years) T0- baseline T1- 3 months after intervention T2- 12 months after the intervention	>Caregivers in the intervention group showed significantly lower levels of depressive symptoms after 3 months and after 12 months but no better sense of competence compared with the control group. >No effects were found on caregiver social-problem solving abilities. (25/26)

		>Patient characteristics SSS, BI, MADRS			
Post et al., 2007, Netherlands	To examine reproducibility of the Carer Strain Index and the Caregiver Reaction Assessment in partners of stroke patients living in the Dutch community	N=47 (CSI n=26, CRA n=21) >Caregivers Majority were female. All participants were partners. Age and gender only reported. Ethnicity, living arrangements and caregiver definition not reported. >Patient characteristics Only age and gender reported	>Quantitative >Comparative study >Repeated administration of self-report postal questionnaires	>CSI >CRA 3 years post stroke as part of a larger study (FuPro-Stroke study)	>The CSI showed good reproducibility and moderate responsiveness versus the CRA which showed insufficient reproducibility and responsiveness. >CSI (N=26) 0.93; 95% confidence interval 0.84 - 0.97 >CRA (N=21) the subscales disrupted schedule, financial schedule and health problems shared sufficient reproducibility. Interclass correlations (ICC) (0.79 - 0.86) but the ICC of the subscales lack of family support (0.67) and self-esteem (0.58) were insufficient. (13/16)
Sedrez- Celich et al, 2016, Brazil	To evaluate the existence of relationship between the burden of family caregivers of individuals with stroke and family support	N=6 >Caregivers Caregiver demographics provided, however, ethnicity, living arrangements and caregiver definition not provided.	>Mixed methods > Qualitative - semi structured interviews >Quantitative – data from ZBI	>ZBI (Brazil version)	>Four out of six were identified with moderate overload and all focused only in the caregiving without any family support. >Caregiver with family support did not become overload had better social life and financially stable. (11/16)

		>Patient characteristics Not reported			
Tang et al., 2011, China	To identify factors associated with burden of Chinese stroke family caregivers	N=123 patient and caregiver pairs (spouses) >Caregivers Caregiver demographic details reported including ethnicity, time spent on caregiving and number of cohabiting family member. Majority female. >Patient characteristics BI, MMSE, GDS	>Quantitative >Cross sectional design >Face to face structured interviews > CBS, CIRS, LSNS, MLES, HADS, MMSE	CBS (20 item Chinese version) Variable	>In the univariate analysis, the CBS score had significant correlations with certain characteristics of caregivers (sex, depressive symptoms, fatigue and modified life event scale) and those of patients' (sex, age, education and Geriatric Depression Scale). >Regression analysis revealed that severity of depressive symptoms in Chinese stroke caregivers and patients' education were independent correlates of the CB Scale. (12/16)
Thommessen 2001, Norway	To describe burden experienced by primary caregiver of elderly stroke patients and identify characteristics that predict subsequent caregiver burden	N=68 patient/caregiver pairs > Caregivers Minimal caregiver demographics provided i.e. age, gender. Caregiver definition, living arrangements and	>Quantitative >Prospective study >Face to face structured interviews >RSS	>RSS >6 months following hospital discharge	>One out of three caregivers reported that they were worried that the patient might have an accident and a similar proportion found it difficult to go on holiday on the RSS. >One in four reported that their social life had been considerably affected and had sleep disturbances on the RSS.

		ethnicity not provided. >Patient characteristics BI, MMSE, MRS, Sodring Motor Evaluation of Stroke Patients			> Impaired cognitive function was the only baseline patient characteristic that predicted subsequent burden on caregivers. (12/16)
Tooth et al., 2005, Australia	To quantify time spent caring, perceived burden and health status in patients of stroke survivors.	N=71 caregivers at 6 months N=57 caregivers at 12 months >Caregivers Demographic information reported except ethnicity. Caregiver definition not reported however, caregiver living arrangements provided. > Patient characteristics FIM, SF-36, Patient demographics including stroke type and stroke side reported.	>Quantitative > Descriptive non-experimental. > Structured interviews >CSI, CBI, SF-36,	>CSI >CBI T1- 6 months T2-12 months	>Caregivers showed considerable burden at 6 and 12 months. Caregivers spent 4.6 hours and 3.6 hours per day assisting patients with daily activities at 6 and 12 months. >Better patient mental health and cognitive function were associated with better caregiver mental health. >Tool validity not reported in this sample. (17/22)
Tosun and Temel, 2017, Turkey	To determine the burden of care	N=66 caregivers	>Quantitative >Cross-sectional design	>ZBI	>Factors associated with burden of care include; income level of family

	among family caregivers of stroke patients	>Caregivers Demographic information provided including whether help was received from other family members and previous experience with caregiving. Ethnicity not reported. >Patient characteristics BI	>Face to face interviews >ZBI, MSPSS	>Variable -less than a year to over 5 years.	member who cared for stroke patient, status of benefitting from home care payment, presence of another person who needs care, duration of providing care, perceived social support and whether family members health status is affected during caregiving. > Cronbach alpha value for ZBI calculated as 0.82 in this study. (12/16).
Tsai et al., 2015, China	To explore changing needs of stroke family caregivers	N=60 patient and caregiver pairs >Caregivers Demographic information provided including religion and living arrangements. Ethnicity and caregiver definition not provided but participants had to be able to speak Mandarin and Taiwanese. >Patient characteristics NIHSS, BI	>Quantitative >Longitudinal study >Self-administered questionnaire >Family needs of stroke patient questionnaire.	>Family needs of stroke patient questionnaire T1 - before discharge from ICU T2 - before hospital discharge T3- 2 weeks post-hospitalisation T4 – 3 months post-hospitalisation	>The total number of family caregiver needs decreased as the illness duration increased. > Although the needs were different at each stage, health information, professional support and community networks were leading need domains in all the stages (T1, T2, T3, T4). >Factors affecting needs of caregivers were NIHSS scores, length of hospital stay and physical dependence of patients. >The overall questionnaire internal consistency reliability for the four stages is 0.89 - 0.93. (17/22)

Vincent et al., 2009, Canada	To compare burden of caregivers of stroke who returned home from two different types of health services and explore predictors of burden.	N=158 patient / caregiver dyads. >Caregivers Demographic information reported except ethnicity. Caregiver definition was not reported as well caregiver living conditions. >Patient characteristics CNS, GDS	>Quantitative >Longitudinal study >Structured interviews >Measure of burden of caregivers of people with disabilities living at home.	Measures of burden of caregivers of people with disabilities living at home. 3 time points post discharge. T1 - 3 weeks T2 - 3 months T3 - 6 months	>Scores on all 3 subscales of burden decreased over time, except for the impact of caregivers' social life (ICSL) subscale that remained stable in the group recruited from the acute hospital. >The best predictors of burden were caregivers' characteristics, i.e. gender (female), occupation (retired), schooling (low), age (older) and hours of care given and stroke survivors characteristics i.e. depressive symptoms, poor motor function (leg), verbal comprehension deficits, difficulty walking and neurological deficits. (17/22)
Zhu and Jiang, 2018, China	To assess caregiver burden of patients with haemorrhagic stroke and its determinants	N=202 patient/caregiver pairs >Caregivers Demographic information provided including living arrangements. Ethnicity and definition of caregiver not provided.	>Quantitative >Longitudinal study >Face to face or telephone structured interviews >BCOS, Self-rated burden scale,	>BCOS 3-time points T1- 1/2 days before hospital discharge T2- 3 months after discharge T3- 6 months after discharge	>Caregiver burden decreased significantly from T1 to T3. >Physical function and depression of stroke survivors plus self-rated burden of caregivers were the most important determinants for overall caregiver burden. (18/22)

		>Patient characteristics BI, SSS, HAM-A, HAM-D,			

Appendix 6: (Continued) Summary review table - quantitative studies (literature review two: tools for assessing family caregivers)
Glossary of quantitative tools

Glossary of quantitative tools	
Abbreviation	Full name
ACS-Revised	Appraisal of Caregiving Scale- Revised (coping)
BAS	Burden Assessment Schedule
BCOS	Bakas Caregiving Outcome Scale
BI	Barthel Index
BSSS	Berlin Social Support Scale
CAS	Carer Assessment Scale
CCTI	Chinese Caregiver Task Inventory
CECS	Courtauld Emotional Control Scale
CES-D	Centre for Epidemiological Studies- Depression
CNS	Canadian Neurological Scale
CPRS	Comprehensive Psychopathological Rating Scale
CRA	Caregiver Reaction Assessment
CSI	Carer Strain Index
CSS	Cognitive Status Scale
EADL	Extended Activities of Daily Living
EBI	Extended Barthel Index
EPI	Eysenck Personality Inventory scale
EuroQol- 5D	EuroQol - five dimensions
FAI	Frenchay Activities Index
F-COPES	Family Crisis Oriented Personal Evaluation Scale
GBB	Giessen Subjective Complaints List
GCS	Glasgow Coma Scale
GDS	Geriatric Depression Scale
HADS	Hospital Anxiety Depression Scale
HADS- A	Hospital Anxiety and Depression Scale – Anxiety
HADS- D	Hospital Anxiety and Depression Scale – Depression
HAM-A	HAM-A Hamilton Rating Scale for Anxiety

HAM-D	HAM-D Hamilton Rating Scale for Depression
IEQ	Intervening Events Questionnaire
KIADL	Katz index of activity of daily life
KOS	Knowledge of stroke scale
Lawton and Browdy IADLs	Lawton and Browdy IADLs- Instrumental Activities of Daily Living
LIFE-3	Life Measure of Well-being-3
LOT	Life Orientation Scale
LSNS	Lubben Social Network Scale
LTS	Leisure Time Satisfaction Questionnaire
MADRS	Montgomery Asberg Depression Rating Scale
MLES	Modified Life Event Scale
MMSE	Mini Mental State Examination
MOS	Medical Outcomes Study (MOS) Social Support Survey
MSPSS	Multidimensional Scale of Perceived Social Support
OCBS	Oberst Caregiving Burden Scale
PCS	Preparedness for Caregiving Scale (adaptation)
POMS	Profile of Mood States Short Form
PPO	Positive Problem Orientation Scale
PSS	Perceived Stress Scale
PANAS	Positive and Negative Affectivity Schedule
RSS	Relative Stress Scale
SCQ	Sense of Competence Questionnaire
SES	Self-Esteem Scale
SF-36	Short-Form 36
SIS	Stroke Impact Study
SIS	Sickness Impact Profile
SOC	Sense of Coherence
SOC -29	Sense of Coherence -29 items
SPMSQ	Short portable Menta status Questionnaire
SRQ	Self-Rated Questionnaire
SSS	Scandinavian Stroke Scale
SSS*	Satisfaction with Stroke Services Scale
SWLS	Satisfaction with Life Scale

UNRS	Unmet Needs Resource Scale
WHOQOL-BREF	World Health Organisation Quality of Life-BREF
ZBI	Zarit Burden Interview

Appendix 7: Summary of tools/scales used to assess burden or needs of family caregivers in the selected studies

Name of Tool	Country	Source	Population of care receiver	Description	Number of items	Items responses	Internal Consistency
An Abbreviated German version of SCQ **(SCQ-German)**	Germany	Pendergrass et al., 2015	Family caregivers of stroke survivors	Shortened from the original tool (SCQ, Vernooij-Dassen et al., 1996) with 27 items. Measures caregivers' feelings of being capable to provide care.	16	4-point scale	0.84
Bakas Caregiving Outcomes Scale **(BCOS)**	USA	Bakas and Champion, 1999	Family caregivers of stroke survivors	Measures adaptation to care giving. It allows both positive and negative experiences to be scored. Higher score indicates positive appraisal. Lower scores indicate greater caregiver burden.	10-12	7-point scale	10 item- 0.9 12 item- 0.77
Burden Assessment Schedule **(BAS)**	India	Thara et al., 1998	Family caregivers of chronic	Measures both subjective and objective burden.	40	3-point scale	0.80

			psychiatric patients				
Caregiver Burden Scale **(CB scale)**	Sweden	Elmstahl, Malmberg and Annerstedt., 1998	Family caregivers of stroke and dementia patients	Five subscales for measuring caregiver burden (general strain, isolation, disappointment, emotional involvement and environment). The total score is obtained by the arithmetical average of the values equivalent to the responses to the specific questions of each dimension.	22	4-point scale	0.70-0.87
Care-giving Burden scale **(CBS)**	Netherlands	Gerristen, 1994	Family caregivers of patients with dementia.	Relationships and consequences of caregiving	13	5 point scale	0.84
Caregiver Burden Inventory **(CBI)**	Canada	Novak and Guest 1989	Family caregivers of elderly with Alzheimer's disease	3 subscales (personal distress, life upset, negative feelings)	24	5 point scale	0.77-0.87

Caregivers Reaction Assessment **(CRA)**	USA	Given et al., 1992	Family caregivers of people with physical impairments, Alzheimer's disease and cancer.	Measures objective and subjective strains and reactions to giving care. Five subscales: carer esteem 7, impact on schedule 5, Lack of family support 5, Impact on finances 3. There is no total score.	24	5 point scale	0.80-0.90
Carer Assessment Scale **(CAS)**	Hong Kong	Mackenzie, Holroyd and Lui, 1998	Family caregivers of Chinese stroke survivors	Generic, holistic assessment of physical, practical, psychological and social needs. Total score range 0-54 with higher scores indicating greater needs.	15	4-point scale	0.80
Carer Strain Index **(CSI)**	USA	Robinson, 1983	Family caregivers of patients recently hospitalised for hip surgery or heart disease.	Measures caregivers' subjective perceptions of the care giving relationship, physical and emotional health. Positive score of 7 or more items indicates high level of burden.	13	Yes/no questions	0.86

Carer Strain Index (Malaysian version) **CSI-M**	Malaysia	Othman and Wong, 2014	Family caregivers of stroke patients	Same as original CSI but translated to Malay language	13	Yes / no questions	0.79
Chinese Caregiver Task Inventory **(CCTI)**	China	Lee et al.,2011	Family caregivers of Chinese older adults	5 subscales: learning to cope with new role, providing care with the carers' needs in mind, managing one's own emotional needs, appraising supportive resources and balancing care giving needs and one's own needs. Higher scores indicate more difficult task. (Shortened from original tool of 45 items)	25 (45 in original tool)	3-point scale	0.93
Family Needs Questionnaire **(FNQ)**	USA	Kreutzer and Marwitz, 1989	Family caregivers of patients with traumatic brain injury	5 subscales: Health information, emotional support, instrumental support, professional support, community support network, involvement with care.	40	4 point scale	0.78- 0.89

Measure of perceived burden of caregivers of people with disabilities living at home	Canada (Montreal)	Dumont et al., 1998 (Original article in French) cited by Vincent et al., 2009	Family caregivers of people living with disability	3 subscales: daily living support (DLS), care recipient's well-being (CCWB), impact on the caregiver's social life (ICSL)	41	3 point scale	DLS - 0.93 CCWB - 0.79 ICSL - 0.86
Modified Montgomery Caregiver Burden Scale **(Montgomery CGS Scale)**	USA	Montgomery, 2000	Family caregiver of elderly patients with chronic illness	3 subscales: subjective, objective and relationship burden	13	5 point scale	0.70 – 0.90
Obsert Caregiving Burden Scale **(OCBS)**	USA	(Oberst, 1990 Unpublished cited in Bakas et al., 2004).	Family caregivers of cancer patients receiving radiotherapy.	Rates 15 different types of care giving tasks for stroke survivors based on perceived time and difficulty. The items of each sub-scale are then summed up (range, 15-75; higher scores indicate greater caregiver burden).	15	5 point scale	0.83-0.89
Perceived Stress Scale **(PSS)**	USA	Cohen and Williamson, 1988	Residents of the US aged 18 years and older	10 item scale. Scores range from 0 to 40, with higher	10	5-point scale	0.78

				scores suggesting high levels of stress.			
Relatives Stress Scale **(RSS)**	UK	Greene et al, 1982	Family caregivers of dementia patients.	15 item scale with 3 subscales: personal distress, life upset and negative feelings.	15	4-point scale	0.70 -0.86
Sense of Competence Questionnaire **(SCQ)**	Netherlands	Vernooij-Dassen et al., 1993	Family caregivers of dementia patients.	3 subscales- caregivers' feelings of being capable of caring for the demented person. The total burden score is the total sum of the item score (27-108). The higher the score, the higher the burden.	27	4-point scale	0.79
Unmet Needs Resource Scale **(UNRS)**	USA	King et al., 2013	Family caregivers of stroke patients	13 items scale addressing family caregivers' access to resources	13	5-point scale	0.84 - 0.88
Zarit Burden Interview **(ZBI)**	USA	Zarit et al., 1980 (Original)	Family caregivers of elderly	Measures perceived burden of caregivers in multi-dimensional aspects (social,	29	5-point scale	0.85

			Alzheimer's patients	physical, financial, emotional burden as well as relation with the care receiver)			

Appendix 8: FREC approval letter exploratory phase (part one)

Edge Hill University

Emmie Malewezi 28th September 2015

Dear Emmie,

Thank you for submitting your revised ethics application 'Adaptation of the Carers' Alert Thermometer (CAT) for use with family carers of stroke survivors- CAT(S): Action Research Study' (FOHS 119) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that I have reviewed your resubmission, and recommended that your study is granted Faculty of Health & Social Care research ethics approval, subject to the following conditions:

1. Ethical approval covers only the original study for which it is sought. If the study is extended, changed, and / or further use of samples or data is needed the Committee Administrator, Daniel Brown, must be contacted for advice as to whether additional ethical approval is required.

2. (NHS studies only) NHS Research governance processes must be adhered to. An application must be made to all NHS R&D departments (in Trusts where data is being collected) for NHS Permissions (previously called Trust R&D approval) to ensure that the study has the necessary permissions granted.

3. If the project requires NHS Permissions and/or NHS ethical approval, please forward evidence of the approval(s) to Daniel Brown (browdan@edgehill.ac.uk) before commencing the study

4. The Principal Investigator is responsible for ensuring that all data are stored and ultimately disposed of securely in accordance with the Data Protection Act (1998) and as detailed within the approved proposal.

The study documentation that has been reviewed and approved is detailed below:

<doc title>	**<version no & date>**
CAT Appendix 1	**V 1.1**
Carer invitation letter – Appendix 2	**V2, September 2015**
Carer information Sheet- Focus Group- Appendix 3	**V2, September 2015**
Carer consent form (focus group) Appendix 4	**V2, September 2015**
Demographic Information Form Appendix 5	**V2, September 2015**
Carer information Sheet- Interviews-Appendix 6	**V2, September 2015**
Carer consent form (interviews) Appendix 7	**V2, September 2015**
Suggested Interview Questions Appendix 8	**V1, August 2015**
CAT(S)_Project_Time Appendix 9	**V1, August 2015**
Emmie Malewezi FREC protocol-Phase one SEPTEMBER 2015	**V2, September 2015**

Yours sincerely

Louise Cope
Acting Chair Faculty of Health & Social Care
Research Ethics Committee

Appendix 9: FREC approval letter exploratory phase (part two)

Edge Hill University

Emmie Malewezi

2nd February 2017

Dear Emmie,

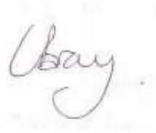
Thank you for submitting your revised ethics documentation for '*Adaptation of the Carers' Alert Thermometer (CAT) for use with family carers of stroke survivors-CAT(S): Action Research Study*' (*FOHS 119*) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that I have reviewed your amended documents and approved the changes made to your research in the submitted documents.

The documentation that have been reviewed and approved is detailed below:

<doc title>	**<version no & date>**
Appendix 2 carer flyer	**V3, February 2017**
Appendix 3 staff flyer	**V3, February 2017**
Appendix 4 Stroke Association web advert	**V3, February 2017**
Appendix 5a Sample invitation email Stroke Association staff	**V3, February 2017**
Appendix 5b Sample invitation email other organisations	**V4, February 2017**
Appendix 9 Sample Preface to online survey (carers)	**V3, February 2017**
Appendix 10 Sample Preface to online survey (staff)	**V3, February 2017**
Appendix 11 Carer Information Sheet (Stroke Association centres)	**V4, February 2017**
Appendix 12 Stroke Association staff Information Sheet	**V4, February 2017**
Appendix 13 Carer questionnaire	**V4, February 2017**
Appendix 14 Staff questionnaire	**V4, February 2017**
Appendix 15 Staff other organisations information sheet	**V2, February 2017**
Appendix 16 Carer Information (stroke association website)	**V2, February 2017**

Yours sincerely



Dr Lucy Bray

Acting Chair of Faculty of Health & Social Care Research Ethics Committee Edge Hill University
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brayl@edgehill.ac.uk

Appendix 10: FREC approval letter (implementation and evaluation phase)

Edge Hill University

Emmie Malewezi

22nd August 2017

Dear Emmie,

Thank you for submitting your research ethics application '*Adaptation of the Carers' Alert Thermometer (CAT) for use with family carers of stroke survivors- CAT(S): Action Research Study*' (FOHS 119) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that the Committee recommended that your study is granted Faculty of Health & Social Care research ethics approval, subject to the following conditions:

1. Ethical approval covers only the original study for which it is sought. If the study is extended, changed, and / or further use of samples or data is needed the Committee Administrator, Daniel Brown, must be contacted for advice as to whether additional ethical approval is required.

2. (NHS studies only) NHS Research governance processes must be adhered to. An application must be made to the HRA for approval for the research to be conducted in the NHS. All NHS R&D departments (in Trusts where data is being collected) will also need to be approached for Trust permission to proceed.

3. If the project requires HRA approval and/or NHS ethical approval, please forward evidence of the approval(s) to Daniel Brown (browdan@edgehill.ac.uk) before commencing the study

4. The Principle Investigator is responsible for ensuring that all data are stored and ultimately disposed of securely in accordance with the Data Protection Act (1998) and as detailed within the approved proposal.

5. The Principle Investigator is responsible for ensuring that an annual monitoring form and an end of study form, where appropriate, is sent to the Committee Administrator (browdan@edgehill.ac.uk). The form will be sent to you at the appropriate time by the Committee Administrator.

6. Ethical approval for this research will expire on 31/10/2017. Any extensions to this date will require additional approval from the committee.

The study documentation that has been reviewed and approved is detailed below:

<doc title>	**<version no & date>**
Research Proposal	**V2, August 2017**
Appendix 1 CAT	**V2**
Appendix 3 Staff Guidance	**V2, August 2017**
Appendix 4 Staff Feedback Form	**V1, June 2017**
Appendix 5 Caregiver consent form	**V1, June 2017**
Appendix 6 Caregiver information sheet	**V1, June 2017**
Appendix 7 Caregiver interview guide	**V1, June 2017**

Yours sincerely

Dr Genevieve Stone

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Appendix 11: Example of a participant information sheet

Edge Hill University

Carers Information Sheet

Assessing the needs of stroke carers study (Interviews)

Research Team: Emmie Malewezi, Prof. Barbara Jack, Dr Mary O'Brien, Dr Juliet Thomas.

Introduction

You are being invited to take part in a research study which aims to help improve the experiences of carers looking after people who have suffered stroke.

Before you decide, it is important for you to understand why the study is being done and what it will involve. Please take the time to read this information carefully and talk to others about the study if you wish.

What is the purpose of this study?

Our study aims to identify issues which carers of stroke survivors find difficult. We want to see if these issues could be reduced if carers were routinely assessed by health and social care staff and then given appropriate support. We also want to find out your views on an alert tool for carers called the Carers' Alert Thermometer (CAT).

Why have I been invited to take part?

We would like to talk to people who are looking after people who have suffered stroke. It is possible that not everyone who is invited to take part will be contacted to be interviewed. We are particularly interested to talk to people who are living at the same address with the person who has suffered stroke.

Do I have to take part?

No. It is up to you to decide if you wish to take part. You are free to withdraw from the study at any time, without having to give a reason. If you decide to withdraw from the study you can contact Professor Barbara Jack on 01695 650768 (Monday to Friday 9am – 5pm) or email her jackb@edgehill.ac.uk.

Thank you for taking the time to read this information

Please keep this information sheet

Appendix 12: Example of a consent form

Edge Hill University

Carer consent form (Interviews)

Assessing the needs of stroke carers

Please initial each box if you agree

1. I confirm that I have read and understand the carer information sheet (interviews) version 2 dated September, 2015 for the above study. I have had the opportunity to consider the information, ask questions, and I am satisfied that I have had all the information that I require. 2.	
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.	
4. I agree to the use of anonymised quotations within reports and publications.	
5. I agree to the take part in the above study and that the discussion can be audio taped.	
6. I understand that data collected during the study may be looked at by individuals from Emmie's supervisory team. I give permission for these individuals to have access to this information.	

_____	_____	_____
Participant Name	Date	Signature
_____	_____	_____
Person taking consent	Date	Signature

1 copy for study file
1 copy for participant

Participant ID:..... (to be completed by researcher)

Appendix 13: Guidelines for the virtual Advisory Group (VAG).

Guidelines for CAT(S) Virtual Advisory Group (VAG)

This advisory group has been created as part of an action research project that is being carried out by researchers at Edge Hill University. The aim of this group is to provide suggestions and guidance on the development of the Carers' Alert Thermometer for stroke family carers- CAT(S). This is an alert tool to identify and support the needs of stroke family carers.

All members of this group have been invited to contribute because they are either a stroke family carer or part of their role involves supporting stroke family carers. Members of this group are based in different locations in the United Kingdom therefore all discussions will be done online via the *CAT(S) virtual advisory group* on wikki (an online discussion platform). This will allow participation from members in different locations from UK.

The following guidelines are here to help you understand what it means to be a member of the *CAT(S) virtual advisory group.*

- This group has members from a wide range of backgrounds and is unlikely to share the same beliefs or opinions. Please be polite and respectful in your interactions with other group members.

- Your contribution is very important and will be used to shape the research project meaning that your active participation will be greatly appreciated.

- Any information discussed or shared within this group is to remain confidential. The exception to this rule is where there is cause to believe that there are safeguarding issues or that a member (or their family) is in danger and needs to be protected. Consequently, the Edge Hill University safeguarding policy will be followed.

- Members of this group will be invited to comment on the different aspects of the study e.g. questions to be asked in the focus groups/interviews, comment on suggested pilot sites and other aspects of the study. In such instances, relevant documents will be uploaded to the wikki group page (an online discussion platform). All members will receive a notification via email about the uploaded documents and they will be given seven days to comment and provide feedback.

- This study has four phases. Members of this group will be informed of the findings at the end of each phase before proceeding to the next phase of the study.

- All members of this group will be mentioned in any future publications under the acknowledgement section unless the group member does not wish this to happen. To opt out please email maleweze@edgehill.ac.uk.

If you have any questions or concerns about this group, please do not hesitate to contact me on 01695 654312 (Monday to Friday 9am -5pm) or email maleweze@edgehill.ac.uk. Alternatively if you prefer to talk to someone outside the research team, you can contact Dr Lucy Bray who is Deputy Chair of the Ethics Committee at Edge Hill University on 01695 657231 or email her brayl@edgehill.ac.uk.

Thank you for taking time to read these guidelines.

Emmie Malewezi
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Email: maleweze@edgehill.ac.uk

Appendix 14: Example of an interview topic guide

Edge Hill University

Interview questions

1. **Demographic information**
   a) Please state the box that best describes your age?

      18-25 ☐ 25-35 ☐ 36-45 ☐ 46-55 ☐ 56-65 ☐ 66-75 ☐76+ ☐

   b) Employment status – current, previous, reasons for stopping work, how long ago stopped work
   c) Ethnicity
   d) Gender
   e) Relationship with person currently caring for

2. **Current caring role**
   a) How long have you looked after .....?
   b) Can you describe some of the things that you do for...? (physical, social, psychological)
   c) Have there been any occasions when you have found caring to be challenging? (Examples & context, what was the most challenging and why? Is emotional impact of stroke an issue?)
   d) What helps you to cope with the challenges? (what helps most, least)

3. **Support and assessments**
   a) What support or help have you received whilst caring for ...?
   b) Is there any help or support you feel you might have benefited from but did not receive?
   c) Did you or.....have the 6 months follow up?
   d) Have you had any assessments since you started caring for ....? (Prompts: Did those assessments result in any additional support?)
   e) What are your thoughts on regular assessments of stroke carers' needs? (Prompts: Any particular areas that you feel needs to be assessed?)
   f) How would you feel being asked about your needs on a regular basis by someone who comes into your home regularly, such as district nurse or stroke coordinator? (Any other professional you would prefer?)

The stroke carers will be shown the Carer Alert Thermometer (CAT)

4. **The Carers' Alert Thermometer (CAT)**
   a) Looking at the items on the CAT, are they appropriate? (Prompts: Are there any items missing? Any examples?)

5. **Open ended question-** Is there anything else you'd like to add to what you've said today?

Thank you for your time

Appendix 15: Invitation letter for distribution to stroke family caregivers

Edge Hill University

Emmie Malewezi
Faculty of Health and Social Care,
Edge Hill University,
Ormskirk,
Lancashire.
L39 4QP
Telephone: 01695 654312
Email: maleweze@edgehill.ac.uk

Invitation Letter

Assessing the needs of stroke carers study

You are being asked to take part in a research study which is looking at the experiences of people caring for family or friends who have had a stroke. The study is being carried out as part of a PhD research project by researchers from the Faculty of Health and Social Care at Edge Hill University.

Before you decide if you would like to take part, please read the accompanying information sheet which explains about the study in more detail. Should you wish to take part in the study you will find details of how this can be done in the information sheet.

If you have any questions or concerns regarding this study, please do not hesitate to contact me through your preferred method using my contact details above.

Yours sincerely,

Emmie Malewezi

Carer invitation letter version-2, September, 2015.

Appendix 16: Modified ranking scale (Van Swieten et al., 1988)

Score Description	Score
No symptoms at all	**0**
No significant disability despite symptoms; able to carry out all usual duties and activities	**1**
Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance	**2**
Moderate disability; requiring some help, but able to walk without assistance	**3**
Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance	**4**
Severe disability; bedridden, incontinent and requiring constant nursing care and attention	**5**
Dead	**6**

Appendix 17: Thematic analysis (Braun and Clarke 2006:87)

Phase one: Familiarising with data	Transcribing data, reading and rereading the data, noting down initial ideas
Phase two: Generating initial code	Coding interesting features of the data systematically across the entire data set, collating data relevant to each code
Phase three: Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
Phase four: Reviewing themes	Checking if the themes work in relation to the coded extracts and entire data set, generating a thematic map
Phase five: Defining and naming themes	Ongoing analysis for refining the specifics of each theme and the overall story that the analysis tells, generating clear definitions and names for each theme
Phase six: Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a report of the analysis

Appendix 18: Example of themes and sub-themes (exploratory phase- part one).

Theme	**Definition**	**Sub-theme**	**Supporting quote (s)**	**Source**
Un met needs	Include responses that relate to any un met needs to support with caring as reported by the caregivers	'a break from caring' (Respite)	"There's times I'll be honest with you…. there's times were you think; oh gosh I can't keep going like this, because I haven't had a day off in that six years, only when *[Husband Name]* ... was in hospital, but then you're running backwards and forwards to hospital..." "but I do just sometimes think that it will be lovely just to put it all to one side and have a break...I mean that's what would help me for him to go to a day centre just so that I could have a little bit of time on my own without worrying what he needs doing..."	P12 P7

Appendix 19: 43 items under eight topics

TOPIC 1: CARING SITUATION **To ask…..**
1) …how long they have been caring for someone who has suffered stroke?
2)...if the carer lives in the same house as the person they care for?
3)…how far away the carer lives if they do not live in the same house as the person they care for?
4)…if the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, caring for grandchildren)
5)…if the carer understands the expected recovery from stroke for the person they are caring for?
6)…if the carer has responsibility for making decisions about the care of the person they care for, as a result of the stroke?
7)…if the carer is accessing any of the support or assistance available to carers?

TOPIC 2: CARING ROLE **To ask…**
8)…if the carer is supporting the person they care for with their medications?
9)…if the carer needs any training to provide care safely, such as lifting and handling or equipment use training?
10)…if the carer requires support to provide personal care (including toileting, washing and dressing, feeding) to the person that they care for?
11)…if the carer needs support to assist with any aspect of rehabilitation of the person they care?
12)...if the carer feels able to manage and cope with the behaviour of the person they care for?
13)...if the carer feels able to support the psychological or emotional needs of the person they care for?
14)…if the carer would like more information on the causes of stroke and how to prevent a further stroke?
15)…if the carer has a named person or number to call with any concerns about the person they care for?

TOPIC 3: RELATIONSHIP WITH HEALTH AND SOCIAL CARE PROFESSIONALS **To ask…**
16)…if the carer is satisfied with the care that professionals are providing to the person they care for e.g. quality of care and how well services work together?
17)…if the carer feels they are receiving the support they need from professionals at the time they need it?
18)…if the carer feels that professionals involve them in decision making by seeking their knowledge and expertise about the care needed by the person they care for?

TOPIC 4: RESPITE AND EMERGENCY CARE **To ask…**
19)…if the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break?
20)…if the carer is satisfied with the quality of any respite care provided? (if used)
21)…if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?

TOPIC 5: FINANCIAL SUPPORT AND ASSESSMENTS **To ask…**
22)…if the carer has any financial worries?
23)…if the carer knows of and has applied for all appropriate funding such as benefits, mobility schemes?
24)…if the person they care for has a social worker?
25)…if the person they care for has been assessed for Continual Health Care funding? (appropriate for patients with complex nursing needs)
26)…if the carer knows what a carer's assessment is?
27)…if the carer has had a carer's assessment?
28)…if the carer is satisfied with the outcome of any assessments that they, or the person they care for, has had? (if appropriate)

TOPIC 6: CARER'S HEALTH AND WELL-BEING **To ask...**
29)...if the carer would like to talk to someone about their own physical well-being?
30)…if the carer would like to talk to someone about their emotional well-being?
31)…if the carer would like help to cope with any aspects of their caring role?
32)…if the person they are caring for is refusing to accept help for themselves or the carer? (e.g. agency carers, sitting service or respite care)
33)…if the carer is able to balance their own health needs with the demands of caring?
34)…if the carer has any ways of coping that they find helpful?
35)…if the carer finds any aspect of caring satisfying?

TOPIC 7: SUPPORT FOR THE CARER **To ask…**
36)…if the carer feels adequately supported by friends, family members or other social networks?
37)…if the carer feels adequately supported in their place of work or study? (if appropriate)
38)…if the carer has received information about the carer support available in their area? (e.g. carers centre, carer support groups)

39)…if the carer feels they are currently getting enough support, or know where to access it when they are ready?
40)…if the carer has received increasing support when the level of care they provide has increased?

TOPIC 8: END OF LIFE AND PLANNING **To ask…**
41)…if the carer knows the wishes and preferences of the person they care for and they have been written down and shared e.g. Advance Care Planning (ACP) document?
42)…if the carer knows what support is available to them before and after the death of the person that they care for?
43)…if the carer needs advice on any legal matters? (e.g. arranging power of attorney).

Appendix 20: Example of the questionnaire in Round 1 of the modified Delphi

Edge Hill University

Survey of Priorities for items to include in the Carers' Alert Thermometer for Stroke CAT(S)

Research team: Emmie Malewezi, Prof. Barbara Jack, Prof. Mary O'Brien, Dr Juliet Thomas

In 2014, with funding from the Department of Health, researchers from Edge Hill University developed the Carers Alert Thermometer (CAT) – an alert tool to identify and support the needs of carers who are supporting a family member or friend with advanced or progressive illness in their own home. As part of a PhD project, the researchers would like to develop an alert tool specifically for use with carers of stroke survivors to be called CAT(S). The CAT(S) will be an alert tool which will be used to regularly identify carers' needs and any increasing areas of burden, in order to trigger further assessments and support. We invite you to share your views on the most important items to be included in the CAT(S).

BACKGROUND TO THE SURVEY
We recently conducted interviews in the North West of England with people caring for a family member or friend who suffered stroke in their home to understand their experiences as carers and their views on the key areas to be included in the proposed CAT(S). We recognise that all of the carers' needs identified in the study so far are important; however, in order for the CAT(S) to be usable it must not be too long. Therefore, the purpose of this survey is to ask a larger number of carers to help us identify which items are the 'most' important to include.

HOW YOU CAN HELP
We would appreciate if you would complete this survey to tell us your views on the most important items to be included in the future CAT(S). Participation is voluntary. You can answer all the questions or just the questions you are comfortable with. Completion of the survey indicates your consent to take part. The survey has 3 sections and should take no more than 30 minutes to complete. All of your responses will remain anonymous.
Please return the completed survey to the person who gave it to you or in the pre-paid self addressed envelope enclosed by **3rd April, 2017.**

Instructions for completing the survey
In section A of the survey items are listed under **8** topics. For each of the items, please circle ONE number on the rating scale to indicate how important you think it is for the item to be included in the future CAT(S), with 1 being 'not at all important', 3 being 'important' and 5 being 'extremely important'. If you do not want to answer any questions in the survey please just put a line through it so we know you have chosen not to answer rather than missed the item. An example is below. Additionally, at the end of each topic, you will be asked to select the most important item that you think should be included on the CAT(S).

TOPIC 1: CARING SITUATION
Thinking about the care provided by carers who are supporting a family member or friend who has suffered stroke, how important is the inclusion of the following items in the CAT(S)?

To ask	*not at all important*	*not very important*	important	Very important	Extremely important
….if the carer sees themselves as a carer?	1	2	3	4	5
…..if the carer lives in the same house as the person they care for?	1	2	3	4	5

Screening Question

Are you currently caring for someone who has suffered a stroke? Yes ☐ No ☐

If your answer is no, you are not eligible to take part in this survey.

SECTION A: TOPICS FOR THE CARER'S ALERT THERMOMETER FOR STROKE CAT(S)

TOPIC 1: CARING SITUATION

Thinking about carers who are supporting a family member or friend at home who suffered a stroke, how important do you think it is to include the following items on the CAT(S)?

To ask ……	not at all important	not very important	important	very important	Extremely important
1)…how long they have been caring for someone who has suffered stroke?	1	2	3	4	5
2)…if the carer lives in the same house as the person they care for?	1	2	3	4	5
3)…how far away the carer lives if they do not live in the same house as the person they care for?	1	2	3	4	5
4)…if the carer has other demands on their time in addition to their caring role? (e.g. working,volunteering, studying, young family, caring for grandchildren)	1	2	3	4	5
5)…if the carer understands the expected recovery from stroke for the person they are caring for?	1	2	3	4	5
6)…if the carer has responsibility for making decisions about the care of the person they care for, as a result of the stroke?	1	2	3	4	5
7)…if the carer is accessing any of the support or assistance available to carers?	1	2	3	4	5

From the list below, please tick ☑ the most important item that you think should be included on the CAT(S). (Please select only ONE)

- How long they have been caring for someone who has suffered stroke? ☐
- If the carer lives in the same house as the person they care for? ☐
- How far away the carer lives if they do not live in the same house as the person they care for? ☐
- If the carer has other demands on their time in addition to their caring role? (e.g. working,volunteering, studying, young family, caring for grandchildren) ☐
- If the carer understands the expected recovery from stroke for the person they are caring for? ☐
- If the carer has responsibility for making decisions about the care of the person they care for, as a result of the stroke? ☐
- If the carer is accessing any of the support or assistance available to carers? ☐

Any comments on Topic 1:

TOPIC 2: CARING ROLE

Thinking about carers who are supporting a family member or friend at home who suffered a stroke, how important do you think it is to include the following items on the CAT(S)?

To ask ……	not at all important	not very important	important	very important	Extremely important
8)…if the carer is supporting the person they care for with their medications?	1	2	3	4	5
9)…if the carer needs any training to provide care safely, such as lifting and handling or equipment use training?	1	2	3	4	5
10)…if the carer requires support to provide personal care (including toileting, washing and dressing, feeding) to the person that they care for?	1	2	3	4	5
11)…if the carer needs support to assist with any aspect of rehabilitation of the person that they care for?	1	2	3	4	5
12)…if the carer feels able to manage and cope with the behaviour of the person they care for?	1	2	3	4	5
13)…if the carer feels able to support the psychological or emotional needs of the person they care for?	1	2	3	4	5
14)…if the carer would like more information on the causes of stroke and how to prevent a further stroke?	1	2	3	4	5
15)…if the carer has a named person or number to call with any concerns about the person they care for?	1	2	3	4	5

From the list below, please tick ☑ the most important item that you think should be included on the CAT(S). (Please select only ONE)

- If the carer is supporting the person they care for with their medications? ☐
- If the carer needs any training to provide care safely, such as lifting and handling or equipment use training? ☐
- If the carer requires support to provide personal care (including toileting, washing and dressing, feeding) to the person that they care for? ☐
- If the carer needs support to assist with any aspect of rehabilitation of the person they care for? ☐
- If the carer feels able to manage and cope with the behaviour of the person they care for? ☐
- If the carer feels able to support the psychological or emotional needs of the person they care for? ☐
- If the carer would like more information on the causes of stroke and how to prevent a further stroke? ☐
- If the carer has a named person or number to call with any concerns about the person they care for? ☐

Any comments on Topic 2:

TOPIC 3: RELATIONSHIP WITH HEALTH AND SOCIAL CARE PROFESSIONALS

Thinking about carers who are supporting a family member or friend at home who suffered a stroke, how important do you think it is to include the following items on the CAT(S)?

To ask ……	not at all important	not very important	important	very important	Extremely important
16)…if the carer is satisfied with the care that professionals are providing to the person they care for e.g. quality of care and how well services work together?	1	2	3	4	5
17)…if the carer feels they are receiving the support they need from professionals at the time they need it?	1	2	3	4	5
18)…if the carer feels that professionals involve them in decision making by seeking their knowledge and expertise about the care needed by the person they care for?	1	2	3	4	5

From the list below, please tick ☑ the most important item that you think should be included on the CAT(S). (Please select only ONE)

- If the carer is satisfied with the care that professionals are providing to the person they care for? e.g. quality of care and how well services work together? ☐
- If the carer feels they are receiving the support they need from professionals at the time they need it? ☐
- If the carer feels that professionals involve them in decision making by seeking their knowledge and expertise about the care needed by the person they care for? ☐

Any comments on Topic 3:

TOPIC 4: RESPITE AND EMERGENCY CARE

Thinking about carers who are supporting a family member or friend at home who suffered a stroke, how important do you think it is to include the following items on the CAT(S)?

To ask ……	not at all important	not very important	important	very important	Extremely important
19)…if the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break?	1	2	3	4	5
20)…if the carer is satisfied with the quality of any respite care provided? (if used)	1	2	3	4	5
21)…if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	1	2	3	4	5

From the list below, please tick ☑ the most important item that you think should be included on the CAT(S). (Please select only ONE)

- If the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break? ☐
- If the carer is satisfied with the quality of any respite care provided? (if used) ☐
- If the carer has planned what should happen in an emergency if they were unable to provide care e.g. If they become ill or go into hospital? ☐

Any comments on Topic 4:

TOPIC 5: FINANCIAL SUPPORT AND ASSESSMENTS

Thinking about carers who are supporting a family member or friend at home who suffered a stroke, how important do you think it is to include the following items on the CAT(S)?

To ask ……..	not at all important	not very important	important	very important	Extremely important
22)…if the carer has any financial worries?	1	2	3	4	5
23)…if the carer knows of and has applied for all appropriate funding such as benefits, mobility schemes?	1	2	3	4	5
24)…if the person they care for has a social worker?	1	2	3	4	5
25)…if the person they care for has been assessed for Continual Health Care funding? (appropriate for patients with complex nursing needs)	1	2	3	4	5
26)…if the carer knows what a carers' assessment is?	1	2	3	4	5
27)…if the carer has had a carer's assessment?	1	2	3	4	5
28)…if the carer is satisfied with the outcome of any assessments that they, or the person they care for, has had? (if appropriate)	1	2	3	4	5

From the list below, please tick ☑ the most important item that you think should be included on the CAT(S). (Please select only ONE)

- If the carer has any financial worries? ☐
- If the carer knows of and has applied for all appropriate funding such as benefits, mobility schemes? ☐
- If the person they care for has a social worker? ☐
- If the person they care for has been assessed for Continual Health Care funding? (appropriate for patients with complex nursing needs) ☐
- If the carer knows what a carers' assessment is? ☐
- If the carer has had a carer's assessment? ☐
- If the carer is satisfied with the outcome of any assessments that they, or the person they care for, has had? (if appropriate) ☐

Any comments on Topic 5:

TOPIC 6: CARER'S HEALTH AND WELL-BEING

Thinking about carers who are supporting a family member or friend at home who suffered a stroke, how important do you think it is to include the following items on the CAT(S)?

To ask ……	not at all important	not very important	important	very important	Extremely important
29)…if the carer would like to talk to someone about their own physical well-being?	1	2	3	4	5
30)…if the carer would like to talk to someone about their emotional well-being?	1	2	3	4	5
31)…if the carer would like help to cope with any aspects of their caring role?	1	2	3	4	5
32)…if the person they are caring for is refusing to accept help for themselves or the carer? (e.g. agency carers, sitting service or respite care)	1	2	3	4	5
33)…if the carer is able to balance their own health needs with the demands of caring?	1	2	3	4	5
34)…if the carer has any ways of coping that they find helpful?	1	2	3	4	5
35)…if the carer finds any aspect of caring satisfying?	1	2	3	4	5

From the list below, please tick ☑ the most important item that you think should be included on the CAT(S). (Please select only ONE)

- If the carer would like to talk to someone about their own physical well-being? ☐
- If the carer would like to talk to someone about their emotional well-being? ☐
- If the carer would like help to cope with any aspects of their caring role? ☐
- If the person they are caring for is refusing to accept help for themselves or the carer? (e.g. agency carers, sitting service or respite care) ☐
- If the carer is able to balance their own health needs with the demands of caring? ☐
- If the carer has any ways of coping that they find helpful? ☐
- If the carer finds any aspect of caring satisfying? ☐

Any comments on Topic 6:

TOPIC 7: SUPPORT FOR THE CARER

Thinking about carers who are supporting a family member or friend at home who suffered a stroke, how important do you think it is to include the following items on the CAT(S)?

To ask ……	not at all important	not very important	important	very important	Extremely important
36)…if the carer feels adequately supported by friends, family members or other social networks?	1	2	3	4	5
37)…if the carer feels adequately supported in their place of work or study? (if appropriate)	1	2	3	4	5
38)…if the carer has received information about the carer support available in their area? (e.g. carers centre, carer support groups)	1	2	3	4	5
39)…if the carer feels they are currently getting enough support, or know where to access it when they are ready?	1	2	3	4	5
40) …if the carer has received increasing support when the level of care they provide has increased?	1	2	3	4	5

From the list below, please tick ☑ the most important item that you think should be included on the CAT(S). (Please select only ONE)

- If the carer feels adequately supported by friends, family members or other social networks? ☐
- If the carer feels adequately supported in their place of work or study? (if appropriate) ☐
- If the carer has received information about the carer support available in their area? (e.g. carers centre, carer support groups) ☐
- If the carer feels they are currently getting enough support, or know where to access it when they are ready? ☐
- If the carer has received increasing support when the level of care they provide has increased? ☐

Any comments on Topic 7:

TOPIC 8: END OF LIFE AND PLANNING

Thinking about carers who are supporting a family member or friend at home who suffered a stroke, how important do you think it is to include the following items on the CAT(S)?

To ask ……	not at all important	not very important	important	very important	Extremely important
41)…if the carer knows the wishes and preferences of the person they care for and they have been written down and shared e.g. Advance Care Planning (ACP) document?	1	2	3	4	5
42)…if the carer knows what support is available to them before and after the death of the person that they care for?	1	2	3	4	5
43)…if the carer needs advice on any legal matters? (e.g. arranging power of attorney)	1	2	3	4	5

From the list below, please tick ☑ the most important item that you think should be included on the CAT(S). (Please select only ONE)

- If the carer knows the wishes and preferences of the person they care for and they have been written down and shared e.g. Advance Care Planning (ACP) document? ☐
- If the carer knows what support is available to them before and after the death of the person that they care for? ☐
- If the carer needs advice on any legal matters? (e.g. arranging power of attorney) ☐

Any comments on Topic 8:

SECTION B: YOUR VIEWS ON THE DEVELOPMENT AND FUTURE USE OF THE CAT(S)

	not at all important	not very important	Important	very important	Extremely important
44) How important do you think is it for carers to have their needs identified?	**1**	**2**	**3**	**4**	**5**

45) Although it will depend on the situation and change over time, how frequently do you think carers' needs should be identified as a minimum? *(Please tick one or state other)*

☐Weekly ☐Monthly ☐Every 3 months ☐Every 6 months

☐Yearly ☐Other.....

46) Which professionals do you think would be best suited to use the CAT(S) with carers of stroke survivors?
You can tick as many as you think appropriate, using the 'Other' comment box to add in any other staff roles. *Please remember that the staff completing the CAT(S) must be able to take action on any need identified whether this is personally, by making referral, or contacting an appropriate person or service to take action.*

☐GP

☐Practice nurses

☐District nurses

☐Community matrons

☐Social workers

☐Stroke Association staff

☐Staff involved with the patient's treatment (doctors, clinical nurse specialists, ward staff)

☐Carer centre staff

☐Community therapists (occupational therapists, physiotherapists, speech & language Therapists)

☐Anyone who has contact with carers

☐Other.....

47) <u>Your Preferences of Topics for the CAT(S)</u>

Listed below are the **8** main topics which are included in this survey. All of these topics are important but we would like you to indicate your preference of topics to be included in the CAT(S) by ranking them from 1st to 8th place. For example, write '1' in the box next to the topic which you consider to be the most important topic to be included, enter '2' for your second most important, and so on until you have ranked all of the 8 topics from 1st to 8th place. Each topic must be ranked as a different place so **<u>please do not use the same number twice.</u>**

Topic 1 Caring situation	
Topic 2 Caring role	
Topic 3 Relationship with health and social care professionals	
Topic 4 Respite and emergency care	
Topic 5 Financial support and assessments	
Topic 6 Carer's health and well-being	
Topic 7 Support for the carer	
Topic 8 End of life and planning	

Any comment about Section B:

SECTION C: YOUR DETAILS

All responses to this survey will remain anonymous but the following questions will help us to know something about the person completing the survey, in terms of your experience as a carer. If you do not want to answer any of the questions in this section please just put a line through it so we know you have chosen not to answer the question. Please respond to the questions by ticking your chosen answer or by writing in the spaces provided.

1) Please tick the box that best describes your age.

☐18-25 ☐26-35 ☐36-45 ☐46-55 ☐56-65 ☐66-75

☐ 76+

2) Are you ☐Male ☐Female ☐ Prefer not to say

3) How would you describe your ethnic group? (Please select only one)

White

☐ English/ Welsh/Scottish/ Northern Irish/British
☐ Irish
☐ Gypsy or Irish Traveller
☐ Any other White background.....(please state)

Mixed/ Multiple ethnic groups

☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other Mixed/ Multiple ethnic background.....(please state)

Asian/Asian British

☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background .....(please state)

Black/African/ Caribbean/ Black British

☐ African
☐ Caribbean
☐ Any other Black/ African/ Caribbean background.....(please state)

Other ethnic group

☐ Arab
☐ Any Other ethnic group.....(please state)

4) Which region of the United Kingdom do you live in?

☐ North East ☐Yorkshire and the Humber ☐East Midlands ☐West Midlands

☐North West ☐South West ☐London ☐South East ☐East of England

☐ Scotland ☐Wales ☐Northern Ireland ☐Other (please state).....

Please answer the following questions thinking about the person that you currently care for?

5) Who do you currently care for? (tick all that apply)

☐Spouse/Partner ☐Child ☐Parent ☐Brother/Sister

☐Grandparent ☐Friend ☐Other...

6) Do you live in the same house as the person you care for? ☐Yes ☐No

7) How long have you been caring?

☐less than 1 year ☐1-2 years ☐3-5 years ☐6-8 years ☐9 years or more

8) On average how many hours a week would you say you care for someone?

☐less than 10 ☐11-20 ☐21-30 ☐31-40 ☐24 hours a day
Other.....

9) Do you currently have other commitments outside of your caring role?

☐ No ☐I'm retired ☐ Work☐Homemaker with children

☐Volunteer ☐Study

10) Did you give up commitments, such as work or study, to care for someone?

☐Yes ☐ No

11) Have you previously cared for someone else who suffered stroke?

☐Yes ☐No

ASSESSMENTS AND SUPPORT (*Please note this section refers to **you** and not the person you care for)*

12) Have you ever had a carer assessment? ☐Yes ☐No ☐Don't Know

13) If Yes, what type of assessment was it? (tick all that apply)

☐Benefits/Financial ☐Social care (social services assessment)

☐Mobility ☐Other……

14) What was the outcome of the assessment?

Any comments on Section C:

If you have any additional comments you would like to make about your experience as a carer please share them here.

Thank you

Thank you for taking the time to complete this survey. We appreciate you giving us your time and expertise to contribute to the development of the CAT(S). Once we have analysed the results of this survey we may find that the number of items people think should be included in the CAT(S) is too high for it to be useful in practice. If we need to reduce it further, we will be sending out a shorter survey containing only the highest rated items by the majority of people who completed this first survey. In the second survey you will see which items were rated most highly by the majority of respondents and have the opportunity to confirm your rating of those items or change it. The final study report will include the responses to both surveys but the questions that have the highest ratings from the second survey will be those considered the most important for inclusion in the CAT(S) which will be evaluated in the next phase of the study.

The second survey will be sent out in the same way as this survey very soon so you should receive it again.

If you have any questions about the study or this survey you can contact Emmie Malewezi on 01695 654312 or the email: maleweze@edgehill.ac.uk.

Please return this completed survey to person who gave it to you or directly to the research team in the pre-paid self addressed envelope enclosed. Please return the survey to Emmie Malewezi by **3rd April, 2017.**

Emmie Malewezi
C/O Dan Brown (EPRC Administrator)
Faculty of Health & Social Care
Edge Hill University
St. Helens Road
Ormskirk
Lancashire
L39 4QP

USEFUL CONTACTS

If completing this survey has raised any concerns for you as a carer or you feel upset about any issue please see listed below the details of some local carer centres across the North West of England and other sources of support and information that may be able to provide help or support.

National Organisations

The Stroke Association

Stroke Association is the leading charity in the UK supporting people affected by stroke and their carers. The Stroke Association provides support and advice to patients and their family carers through the national help line or regional offices. They also have affiliated stroke clubs.

To find more information please call the helpline or visit the website.

National Helpline:0303 3033 100

Website:https://www.stroke.org.uk

Email: info@stroke.org.uk

Carers Trust

This is a charity which was formed by the merger of The Princess Royal Trust for Carers and Crossroads Care in April 2012. Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

To find details of your local carer centre please visit the website or call the helpline.

Website: http://www.carers.org

Helpline: 0844 800 4361

Carer Centres in the North West

There are a number of carers' centres across the North West who all provide support and advice to carers either in the centre, on the phone or sometimes at home. Below are a few of those available.

Halton Carers' Centre provides support for unpaid carers' of all ages who care for someone who has a disability or illness and lives in Halton.

Website: http://www.haltoncarers.co.uk

Helpline: 01928 580182 or 0151 257 9673

Sefton Carers' Centre provides information, advice and support to carers in ways which are sensitive to their needs and wishes through the provision of a one-stop-shop in Waterloo.

Website: http://www.sefton-carers.co.uk

Helpline: 0151 288 6060

St Helen's Carers' Centre is an independent registered charity which is governed by carers and works to improve the quality of life for unpaid carers in the borough of St Helens.

Website: http://www.sthelenscarers.org.uk
Helpline: 01744 675 615

The West Lancashire Carers' Centre informs, supports, promotes and fund carers and parents' health and social care services and activities, and they listen to, inform carers and parents with practical help.
Website: http://www.prtwlcarers.org.uk/
Helpline: 01695 71124

Appendix 21: Example of a flyer advertising the study

Edge Hill University

CALLING CARERS WHO LIVE WITH AND SUPPORT STROKE SURVIVORS

CAT CARERS' ALERT

HAVE YOUR SAY ABOUT THE SUPPORT FOR CARERS OF STROKE SURVIVORS

Please take part in a survey to develop a new tool to help carers of stroke survivors get the right support at the right time.

Researchers from Edge Hill University are developing a Carers' Alert Thermometer for use with carers who support stroke survivors to be called CAT (S). The CAT (S) will be used regularly to identify if carers of stroke survivors could receive additional information or support. We conducted interviews on the key areas to be included in the proposed CAT(S). All of the carers' needs identified in the study are important; but in order for the CAT(S) to be used regularly it must not be too long. This survey will enable a larger number of carers and staff to help us identify which items are the '*most*' important to include.

HOW YOU CAN HELP

We would appreciate it if you would complete this survey to tell us your views on which are the most important items to be included in the future CAT(S) which will be used to identify the needs of those currently caring for a family member or friend at home who suffered stroke. The survey has 3 sections and should take no more than 30 minutes to complete. All of your responses will remain anonymous.

After analysing the results of the survey, we may find that the number of items people think should be included in the CAT(S) is too high for it to be useful in practice. If we need to reduce it further, we will send out a shorter survey containing the highest rated items by the majority of the people who completed the first survey.

The survey is available online at:
https://www.surveymonkey.co.uk/r/CAT-S-C1

Alternatively there is a paper copy of the survey available with a pre-paid envelope in the centre. Please return the completed survey in the pre-paid envelope provided.

The closing date for online and paper surveys is **Monday 13th March, 2017.**

If you have any questions about the study, please contact Emmie Malewezi on Tel: 01695 654315 (Monday to Friday 9am - 5pm).
Email: maleweze@edgehill.ac.uk

Stroke Association centres (carers flyer) version 3, February, 2017.

Appendix 22: The CAT-S used for pilot

Pilot Carers' Alert Thermometer for Stroke (CAT-S)

Edge Hill University

INSTRUCTIONS

Section 1 and 2 to be completed together, ticking the level of need for any alerts which could impact on (a) the care being provided or (b) the carer's own well-being;

L NO or LOW need I INTERMEDIATE need H HIGH need

Section 3 circle the total number of **intermediate** (amber) and **high needs** (red) alerts on the thermometer;

Section 4 make a plan with the carer; prioritising the top four alerts for action and noting the agreed next steps for the priority alerts identified;

Section 5 set a review date and person responsible for follow up. All questions to be revisited during a review to monitor the support provided and any change in the alerts. It is recommended that monitoring and review dates be more frequent for carers with alerts which are considered 'HIGH' (red) or 'INTERMEDIATE' (amber).

SECTION 1: PLEASE COMPLETE THE DETAILS BELOW

Date CAT-S completed:.....

Gender:..... Age:..... How long have you been a carer?.....

Relationship to person you are caring for: (circle) Spouse / Parent / Child / Sibling / Friend / Other:.....

Carers Assessment completed? (circle) Yes No Unsure

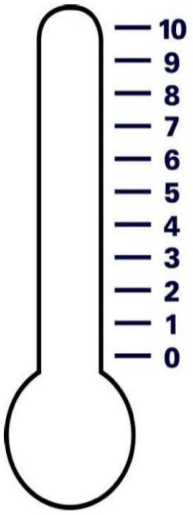
SECTION 2: IDENTIFY & ASSESS THE NEEDS OF THE CARER

This section contains questions to identify areas of need that carers may experience. Please go through each question together circling the level of need identified, even if no needs or concerns are identified at Q1.

[x] = person being cared for e.g. husband or wife.

A. CURRENT CARING SITUATION **Q1. Do you currently have any needs or concerns about caring for your [x] or your own health and well-being?** *(please circle one)* **Yes No Unsure**			
Q2. Do you need any information about the stroke your [x] has had and the expected recovery?	L	I	H
Q3. Do you require any training or support to provide care safely e.g. lifting and handling use equipment?	L	I	H
Q4. Do you need support to manage the behaviour of your [x]	L	I	H
Q5. Do you have any specific plans in place in the event of an emergency?	L	I	H
B. CARER'S HEALTH AND WELL-BEING **Q6.** Do you feel involved in decision making and listened to by professionals about the care needed by [x]	L	I	H
Q7. Do you need support to help manage your own emotions e.g. a listening ear or someone to talk to?	L	I	H
Q8. Do you need a break from caring during the day or overnight?	L	I	H
Q9. Do you have any other demands on your time in addition to your caring role? (e.g. working, young family, caring for grandchildren)	L	I	H
If appropriate include: **Q10.** Do you know your [x]'s wishes and preferences for EoL care? (If known, have they been written down and shared, e.g. advance care planning (ACP) doc?)	L	I	H
Sub-total of amber and red alerts			

SECTION 3.
CIRCLE THE TOTAL NUMBER OF AMBER AND RED ALERTS ON THE THERMOMETER SCALE



SECTION 4: SUGGESTED NEXT STEPS Some general guidance is included below which can be amended by managers or senior clinicians of the service to help guide staff responses when conducting the CAT-S based on available local services and support.

Q1	If no needs raised with this opening question continue with the rest of the CAT-S. If there are needs raised, listen to them now before progressing with the CAT-S, as it will help to guide you about the carer's priorities.
Q2	Provide information to the carer if appropriate or refer to the appropriate professional or stroke team.
Q3	Identify area of need and provide information or onward referral as appropriate.
Q4	Discuss local & national sources of support for the carer & advise on routes of support for the patient e.g. GP, counselling services, community stroke teams.
Q5	If not, ensure carer knows about the GP out-of-hours service or similar (e.g. Local Stroke Association helpline)
Q6	Discuss carer's concerns; if appropriate, liaise with appropriate health & social care professionals.
Q7	Provide information on local services e.g. local carer centre or Stroke Association emotional support services.
Q8	Provide information about local authority carer assessments, local respite care or sitting services if available.
Q9	Provide information about local services and support e.g. carer centre, support group meetings.
Q10	If appropriate, ask if they would like information on Advance Care Planning.

SECTION 5: PLAN. Use this table to briefly note the details of <u>up to four priority alerts requiring action now</u>, any actions taken today, and any next steps which have been agreed with the carer.

Brief summary of needs identified by alerts (If there are several needs, ask the carer to "*identify which one thing would help you most at this time?*")	**Any immediate action taken** e.g. information clarified, verbal or written information given, referred to see other health care professional	**Any next steps required?** e.g. Referral to other services, speak to Team Leader/Manager for advice on next steps	**Who is responsible for the next step or follow up?**	**Date of review or follow up**

SECTION 6: Date of next review:…… with……

SECTION 7: Time taken to complete this CAT-S form ……

Appendix 23: Staff guidance sheet used during the CAT-S pilot

Carers' Alert Thermometer for Stroke-CAT(S) Pilot guidance for Community Stroke Coordinators

Edge Hill University

Thank you for agreeing to take part in the piloting of the Carers Alert Thermometer for use with caregivers who support stroke survivors called CAT(S). Below are some short guidance notes to help you identify eligible participants to use the CAT(S) with, and on the process of the pilot evaluation.

Caregiver Inclusion Criteria

The CAT(S) is designed to be used with **unpaid caregivers** who are supporting a family member who suffered a stroke. Please use the following criteria to identify eligible caregivers for the pilot:

- Adults and young persons aged 18+ years;
- Able to speak English
- Caregiver is residing at the same address with the stroke survivor
- The caregiver consents to take part in the pilot which includes (i) completing the CAT(S) & (ii) a short face to face interview.

Procedure

STEP 1: When an appropriate caregiver is identified, the community stroke coordinator will post the participant information sheet approximately a week in advance of a scheduled routine home visit to the participant's home. On the day of the visit, the community stroke coordinator will check and confirm if the caregiver has received and read the participant information sheet and whether they have considered taking part.

STEP 2: If the caregiver agrees to take part, the stroke coordinator should assist the caregiver to complete the caregiver consent form and then complete the pilot CAT(S) with them. On completion of the CAT(S) the stroke coordinator will give the caregiver a list of the local support services available to caregivers and take any appropriate actions agreed on the CAT(S) e.g. providing information or discussing an alert with a manager.

STEP 3: The stroke coordinator should then complete the staff feedback form and upon returning to their office, securely store the staff feedback form, the caregiver consent form and the completed pilot CAT(S) in a locked cupboard in the Managers office waiting to be collected by a member of the research team. Completion of the CAT(S) and the staff feedback form indicates your consent to take part.

Completing the CAT(S)

FRONT PAGE: Please follow the instructions on the front page to complete Section 1, 2 and 3 with the caregiver. Give the caregiver a printed list with contact details of the local support services available in the area.

BACK PAGE: Use the 'Suggested Next Steps' to guide your responses to any alerts raised by the caregiver. Complete Section 4 for the alerts identified (prioritising if necessary) and provide brief details of any next steps to be taken or followed up. Complete the data requested in the final section of the form.

For the caregivers who become involved at the beginning of the evaluation period, it may be possible to conduct the CAT(S) more than once with individual caregivers if the stroke coordinators feels this is appropriate. If the caregiver does complete the CAT(S) more than once they will only be approached by the research team after the final time has been completed to arrange their interview but the stroke coordinator will be asked to complete the feedback form each time the pilot CAT(S) is used to identify any changes in comments as the CAT(S) is used more frequently or the caregiver's needs increase.

Timeline

The evaluation period will run from Monday [dates to be entered once approval received from FREC] or up to a maximum number of caregivers agreed.

Research Team Contact Details

If you would like to talk about the study or have any questions or concerns during the pilot please contact **Emmie Malewezi** on 01695 654312 (Monday to Friday 9am - 5pm) or email maleweze@edgehill.ac.uk.

Appendix 24: Staff feedback form

Carers Alert Thermometer for Stroke – CAT(S) (pilot version)

STAFF FEEDBACK FORM

Edge Hill University

Thank you for completing the pilot CAT(S) with a caregiver. Please fill in this feedback form by circling your response or providing a comment to each question in Section A. Additional comments about the CAT(S) can be made in the Section B at the end. (*If you have previously completed a feedback form you can ignore the greyed areas unless you wish to add to your previous views).* **Please return the feedback form with the completed CAT(S) and Caregiver Interview Consent Form to the research team (see staff guidance).**

SECTION A: Questions	Circle response	Any comments
1. Did you find the CAT(S) instructions easy to follow?	YES NO	
2. Did the questions read well (make sense)?	YES NO	
3. Were there any important questions missing from the CAT (S) generally or in relation to this caregiver?	YES NO	
4. Did the questions lead to further appropriate discussion with the caregiver?	YES NO	
5. Did the questions identify any needs for this caregiver that would have remained undetected if the CAT(S) had not been conducted?	YES NO	
6. Do you think the CAT(S) could identify areas of risk for the caregiver or the care they provide to the stroke survivor?	YES NO	
7. Would you use the CAT(S) with caregivers in the future?	YES NO	
8. Are there any particular groups of family caregivers that you would view as a priority to use the CAT(S) with?	YES NO	
9. Do you think the CAT(S) could be conducted electronically? e.g. ipad or computer	YES NO	
10. If the CAT(S) was being used regularly with a caregiver, where do you think the CAT(S) should be stored? *(considering confidentiality)*		
11. Which staff groups do you think could use the CAT(S) with caregivers of stroke survivors?		
12. At what point in the stroke survivors' journey do you think the CAT(S) should be used with family caregivers?		

SECTION B – Please add any additional comments you would like to make about using the CAT(S) and its potential future use with caregivers here or on the back of the form.

Staff details: Name:…… **Contact Tel:**.....**Email:**.....

Appendix 25: Interview guide (Evaluation phase)

Edge Hill University

Assessing the needs of caregivers who support stroke survivors

Caregiver interview guide CAT(S) pilot

This will be a short interview to gather some background on the caregivers' role and to ask about their experience of using the pilot CAT(S). Topics for the interview may include:

Current caring role

1. How long have you have you looked after [x]?

CAT(S)

I'd like to ask you about your experience of completing the CAT(S) with [name of community stroke coordinator].

2. What are your comments on the length of time it took to complete the CAT(S) with the community stroke coordinator? *(Too long/short? Just right?)*
3. What are your views about the questions on the CAT(S)?
4. Did the questions lead to discussion about any needs or concerns you have?
    a. *(If so, which areas?)*
5. Did the questions lead to you receiving any information or identify any actions needed to provide you with some support?
    a. *(If so, what support, who?)*
6. Did you find there were any needs or concerns that you have which were not included on the CAT(S)?
7. From the alerts identified (if any) when you completed the CAT(S), is there any help or support you feel you would benefit from?
8. What are your views about the list of contact details of the local support services that you were given at the end helpful?
9. What are your comments about the staff's approach in relation to your needs and concerns whilst completing the CAT(S)? *(i.e. did you feel listened to? If not, if not, what would make you feel more listened to about your concerns? i.e. questions, staff member's approach….?*

Future CAT(S) use

10. What are your thoughts about regular assessment of caregivers needs with the CAT(S)? *(positive, negative, any specific areas)*
11. If a staff member was to ask you about your needs or concerns as a family caregiver on a regular basis, who would you want it to be done by? *(Is this someone who comes into the home at the moment for the care of [person being cared for]?)*

Open ended question: Is there anything else you would like to say about using the CAT(S) that you would like to say before we finish?

Appendix 26: Round 1 analysis (family caregivers, staff and total sample

Responses to Topics 1-8 in Round 1

Participants from both cohorts rated **43 items across 8 main topics** on a 5-point Likert scale, with 1 being *'not at all important'*, 3 being '*important'* and 5 being '*extremely important'*. The table below presents the sample numbers, median and IQR for each item for each cohort and the total sample along with the % that met the criteria for inclusion. The items highlighted are those that did not meet the pre-determined 70% consensus criteria and were excluded.

TOPIC 1: CARING SITUATION **How important is it to ask…**										
	Total sample (N)	**Total sample median (IQR)**	**Consensus rate* (%)**	**Staff (N)**	**Staff median (IQR)**	**Consensus rate* (%)**	**Family caregivers (N)**	**Family caregivers median (IQR)**	**Consensus rate* (%)**	**Criteria****
1) …how long they have been caring for someone who has suffered stroke?	113	4.0 (2.0)	66	101	4.0 (2.0)	66	12	4.0 (2.0)	67	Not met
2)...if the carer lives in the same house as the person they care for?	113	4.0 (1.0)	84	101	4.0 (1.0)	82	12	4.5 (1.0)	100	Met
3)…how far away the carer lives if they do not live in the same house as the person they care for?	113	4.0 (2.0)	63	101	4.0 (2.0)	62	12	5.0 (1.8)	67	Not met
4)…if the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, caring for grandchildren)	113	5.0 (1.0)	91	101	5.0 (1.0)	90	12	5.0 (0.8)	100	Met

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate*	Family caregivers (N)	Family caregivers median (IQR	Consensus rate* (%)	Criteria**
5)…if the carer understands the expected recovery from stroke for the person they are caring for?	113	5.0 (1.0)	78	101	4.0 (1.0)	77	12	5.0 (1.0)	83	Met
6)…if the carer has responsibility for making decisions about the care of the person they care for, as a result of the stroke?	113	4.0 (1.0)	80	101	4.0 (1.0)	78	12	4.5 (1.0)	92	Met
7)…if the carer is accessing any of the support or assistance available to carers?	113	5.0 (1.0)	85	101	5.0 (1.0)	84	12	5.0 (1.0)	92	Met
TOPIC 2: CARING ROLE **How important is it to ask…**										
8)…if the carer is supporting the person they care for with their medications?	113	4.0 (2.0)	65	101	4.0 (2.0)	64	12	5.0 (1.8)	75	Disagreement
9)…if the carer needs any training to provide care safely, such as lifting and handling or equipment use training?	113	5.0 (1.0)	89	101	5.0 (1.0)	92	12	4.5 (1.8)	67	Disagreement

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate*	Family caregivers (N)	Family caregivers median (IQR	Consensus rate* (%)	Criteria**
10)…if the carer requires support to provide personal care (including toileting, washing and dressing, feeding) to the person that they care for?	113	5.0 (1.0)	90	101	5.0 (1.0)	92	12	5.0 (1.0)	75	Met
11)…if the carer needs support to assist with any aspect of rehabilitation of the person they care?	113	4.0 (1.0)	77	101	4.0 (1.0)	77	12	4.5 (1.0)	75	Met
12)...if the carer feels able to manage and cope with the behaviour of the person they care for?	113	5.0 (1.0)	95	101	5.0 (1.0)	95	12	5.0 (1.0)	92	Met
13)...if the carer feels able to support the psychological or emotional needs of the person they care for?	113	5.0 (1.0)	89	101	5.0 (1.0)	87	12	5.0 (1.0)	100	Met
14)…if the carer would like more information on the causes of stroke and how to prevent a further stroke?	113	4.0 (1.0)	59	101	4.0 (1.0)	58	12	4.0 (2.0)	67	Not met

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR	Consensus rate* (%)	Criteria**
15)…if the carer has a named person or number to call with any concerns about the person they care for?	113	5.0 (1.0)	90	101	5.0 (1.0)	91	12	5.0 (0.0)	83	Met
TOPIC 3: RELATIONSHIP WITH HEALTH AND SOCIAL CARE PROFESSIONALS **How important is it to ask...**										
16)…if the carer is satisfied with the care that professionals are providing to the person they care for e.g. quality of care and how well services work together?	113	4.0 (2.0)	61	101	4.0 (1.5)	59	12	5.0 (1.0)	83	Disagreement
17)…if the carer feels they are receiving the support they need from professionals at the time they need it?	113	4.0 (1.0)	81	101	4.0 (1.0)	79	12	5.0 (0.0)	92	Met
18)…if the carer feels that professionals involve them in decision making by seeking their knowledge and expertise about the care needed by the person they care for?	113	4.0 (1.0)	79	101	4.0 (1.0)	79	12	5.0 (1.0)	75	Met

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR	Consensus rate* (%)	Criteria**
TOPIC 4: RESPITE AND EMERGENCY CARE **How important is it to ask…**										
19)…if the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break?	113	4.0 (1.0)	84	101	4.0 (1.0)	86	12	4.5 (1.8)	67	Disagreement
20)…if the carer is satisfied with the quality of any respite care provided? (if used)	113	4.0 (1.0)	60	101	4.0 (1.0)	59	12	4.0 (1.8)	75	Disagreement
21)…if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	113	5.0 (1.0)	86	101	5.0 (1.0)	86	12	5.0 (1.0)	83	Met
TOPIC 5: FINANCIAL SUPPORT AND ASSESSMENTS **How important is it to ask…**										
22)…if the carer has any financial worries?	113	4.0 (2.0)	68	101	4.0 (2.0)	66	12	5.0 (1.0)	83	Disagreement

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR	Consensus rate* (%)	Criteria**
23)…if the carer knows of and has applied for all appropriate funding such as benefits, mobility schemes?	113	4.0 (1.0)	82	101	4.0 (1.0)	82	12	5.0 (1.0)	83	Met
24)…if the person they care for has a social worker?	113	4.0 (1.0)	55	101	4.0 (1.0)	56	12	4.0 (1.8)	50	Not met
25)…if the person they care for has been assessed for Continual Health Care funding? (appropriate for patients with complex nursing needs)	113	4.0 (2.0)	51	101	4.0 (2.0)	50	12	4.0 (1.8)	58	Not met
26)…if the carer knows what a carer's assessment is?	113	4.0 (2.0)	68	101	4.0 (2.0)	66	12	4.0 (1.0)	83	Disagreement
27)…if the carer has had a carer's assessment?	113	4.0 (1.0)	79	101	4.0 (1.0)	79	12	4.0 (1.0)	75	Met
28)…if the carer is satisfied with the outcome of any assessments that they, or the person they care for, has had? (if appropriate)	113	4.0 (1.0)	61	101	4.0 (1.0)	60	12	4.0 (1.0)	75	Disagreement

TOPIC 6: CARER'S HEALTH AND WELL-BEING How important is it to ask…										
	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR)	Consensus rate* (%)	Criteria**
29)...if the carer would like to talk to someone about their own physical well-being?	113	4.0 (2.0)	67	101	4.0 (2.0)	66	12	5.0 (0.8)	75	Disagreement
30)…if the carer would like to talk to someone about their emotional well-being?	113	4.0 (1.0)	79	101	4.0 (1.0)	79	12	5.0 (1.0)	75	Met
31)…if the carer would like help to cope with any aspects of their caring role?	113	5.0 (1.0)	86	101	5.0 (1.0)	88	12	5.0 (1.0)	67	Disagreement
32)…if the person they are caring for is refusing to accept help for themselves or the carer? (e.g. agency carers, sitting service or respite care)	113	4.0 (2.0)	68	101	4.0 (2.0)	69	12	4.5 (1.8)	58	Not met
33)…if the carer is able to balance their own health needs with the demands of caring?	113	4.0 (1.0)	81	101	4.0 (1.0)	80	12	5.0 (1.0)	83	Met

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR)	Consensus rate* (%)	Criteria**
34)…if the carer has any ways of coping that they find helpful?	113	4.0 (1.5)	63	101	4.0 (1.0)	63	12	4.0 (1.8)	58	Not met
35)…if the carer finds any aspect of caring satisfying?	113	3.0 (1.0)	43	101	3.0 (1.0)	44	12	4.0 (1.8)	42	Not met
TOPIC 7: SUPPORT FOR THE CARER **How important is it to ask…**										
36)…if the carer feels adequately supported by friends, family members or other social networks?	113	4.0 (1.5)	60	101	4.0 (1.0)	59	12	4.5 (1.8)	67	Not net
37)…if the carer feels adequately supported in their place of work or study? (if appropriate)	113	3.0 (1.0)	47	101	3.0 (1.0)	47	12	4.0 (2.5)	50	Not met
38)…if the carer has received information about the carer support available in their area? (e.g. carers centre, carer support groups)	113	4.0 (1.0)	77	101	4.0 (1.0)	77	12	4.0 (1.0)	75	Met
39)…if the carer feels they are currently getting enough support, or know where to access it when they are ready?	113	5.0 (1.0)	89	101	5.0 (1.0)	89	12	5.0 (1.0)	83	Met

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR)	Consensus rate* (%)	Criteria**
40)…if the carer has received increasing support when the level of care they provide has increased?	113	4.0 (2.0)	71	101	4.0 (2.0)	73	12	4.0 (2.0)	50	Disagreement
TOPIC 8: END OF LIFE AND PLANNING **How important is it to ask…**										
41)…if the carer knows the wishes and preferences of the person they care for and they have been written down and shared e.g. Advance Care Planning (ACP) document?	113	4.0 (1.0)	82	101	4.0 (1.0)	83	12	5.0 (1.0)	75	Met
42)…if the carer knows what support is available to them before and after the death of the person that they care for?	113	4.0 (2.0)	73	101	4.0 (2.0)	73	12	5.0 (0.8)	67	Disagreement
43)…if the carer needs advice on any legal matters? (e.g. arranging power of attorney).	113	4.0 (1.0)	76	101	4.0 (1.0)	78	12	5.0 (1.8)	58	Disagreement

**Consensus rate- percentage of respondents who rated the item 4 'Very important' or 5 'Extremely important'.*
*** Criteria- If 70% met, retain item, if not met then, remove item, if disagreement between cohorts then, re-rate item*

Appendix 27: Round 2 analysis (family caregivers, staff and total sample)

Responses to Topics 1-8 in Round 2

Participants from both cohorts rated **33 items across 8 main topics** on a 5-point Likert scale, with 1 being 'not at all important', 3 being 'important' and 5 being 'extremely important'. The table below presents the sample numbers, median and IQR for each item for each cohort and the total sample along with the % that met the criteria for inclusion. Items highlighted are those that did not meet the pre-determined 70% consensus criteria and were excluded.

TOPIC 1: CARING SITUATION **How important is it to ask…**											
	Total sample (N)	**Total sample median (IQR)**	**Consensus rate** (%)**	**Staff (N)**	**Staff median (IQR)**	**Consensus rate* (%)**	**Family caregivers (N)**	**Family caregivers median (IQR)**	**Consensus rate** (%)**	**Total sample mean (SD)**	**Criteria****
1) …if the carer lives in the same house as the person they care for?	136	4.0 (1.0)	75	117	4.0 (1.0)	77	19	4.0 (2.0)	63	4.22 (.89)	Disagreement
2) …if the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, caring for grandchildren)	136	5.0 (0.0)	90	117	5.0 (0.0)	94	19	4.0 (2.0)	69	4.64 (.70)	Disagreement
3) …if the carer understands the expected recovery from stroke for the person they are caring for?	136	5.0 (1.0)	88	117	5.0 (1.0)	91	19	4.0 (2.0)	68	4.50 (.76)	Disagreement

	Total sample (N)	Total Sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR)	Consensus rate* (%)	Total sample mean (SD)	Criteria**
4) …if the carer has responsibility for making decisions about the care of the person they care for, as a result of the stroke?	136	5.0 (1.0)	86	117	5.0 (1.0)	87	19	4.0 (1.0)	79	4.41 (.78)	Met
5) …if the carer is accessing any of the support or assistance available to carers?	136	5.0 (1.0)	87	117	5.0 (1.0)	90	19	4.0 (2.0)	68	4.47 (.74)	Disagree ment
TOPIC 2: CARING ROLE **How important is it to ask…**											
6) …if the carer is supporting the person they care for with their medications?	136	4.0 (2.0)	57	117	4.0 (2.0)	66	19	4.0 (1.0)	79	4.03 (.92)	Disagree ment
7) …if the carer needs any training to provide care safely, such as lifting and handling or equipment use training?	136	5.0 (1.0)	91	117	5.0 (1.0)	94	19	4.0 (2.0)	74	4.58 (.64)	Met
8) …if the carer requires support to provide personal care (including toileting, washing and dressing, feeding) to the person that they care for?	136	5.0 (1.0)	90	117	5.0 (1.0)	93	19	5.0 (2.0)	69	4.57 (.69)	Disagree ment

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate*(%)	Family caregivers (N)	Family caregivers median (IQR)	Consensus rate* (%)	Total sample mean (SD)	Criteria**
9) …if the carer needs support to assist with any aspect of rehabilitation of the person they care?	136	4.0 (1.0)	81	117	4.0 (1.0)	81	19	4.0 (1.0)	79	4.26 (.78)	Met
10) ...if the carer feels able to manage and cope with the behaviour of the person they care for?	136	5.0 (1.0)	93	117	5.0 (0.0)	94	19	4.0 (1.0)	84	4.64 (.61)	Met
11) ...if the carer feels able to support the psychological or emotional needs of the person they care for?	136	5.0 (1.0)	90	117	5.0 (1.0)	92	19	5.0 (1.0)	79	4.54 (.67)	Met
12) …if the carer has a named person or number to call with any concerns about the person they care for?	136	5.0 (1.0)	90	117	5.0 (1.0)	90	19	4.0 (1.0)	89	4.54 (.67)	Met
TOPIC 3: RELATIONSHIP WITH HEALTH AND SOCIAL CARE PROFESSIONALS **How important is it to ask…**											
13) …if the carer is satisfied with the care that professionals are providing to the person they care for e.g. quality of care and how well services work together?	136	4.0 (1.0)	63	117	4.0 (1.0)	62	19	4.0 (2.0)	68	N/A	Not met

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR	Consensus rate* (%)	Total sample mean (SD)	Criteria**
14) …if the carer feels they are receiving the support they need from professionals at the time they need it?	136	4.0 (1.0)	86	117	4.0 (1.0)	88	19	5.0 (1.0)	74	4.28 (.73)	Met
15) …if the carer feels that professionals involve them in decision making by seeking their knowledge and expertise about the care needed by the person they care for?	136	4.0 (1.0)	84	117	4.0 (1.0)	83	19	5.0 (1.0)	90	4.29 (.75)	Met
TOPIC 4: RESPITE AND EMERGENCY CARE **How important is it to ask…**											
16) …if the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break?	136	4.0 (1.0)	85	117	4.0 (1.0)	89	19	4.0 (2.0)	58	4.30 (.74)	Disagree ment
17) …if the carer is satisfied with the quality of any respite care provided? (if used)	136	4.0 (1.0)	68	117	4.0 (1.0)	69	19	4.0 (1.0)	63	N/A	Not Met

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR	Consensus rate* (%)	Total sample mean (SD)	Criteria**
18) …if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	136	5.0 (1.0)	89	117	5.0 (1.0)	90	19	4.0 (1.0)	84	4.54 (.68)	Met
TOPIC 5: FINANCIAL SUPPORT AND ASSESSMENTS **How important is it to ask…**											
19) …if the carer has any financial worries?	136	4.0 (2.0)	71	117	4.0 (2.0)	72	19	4.0 (2.0)	68	4.03 (.80)	Met
20) …if the carer knows of and has applied for all appropriate funding such as benefits, mobility schemes?	136	4.0 (1.0)	84	117	4.0 (1.0)	85	19	4.0 (1.0)	79	4.22 (.70)	Met
21) …if the carer knows what a carer's assessment is?	136	4.0 (0.0)	73	117	4.0 (0.0)	74	19	4.0 (1.0)	74	3.99 (.85)	Met
22) …if the carer has had a carer's assessment?	136	4.0 (1.0)	77	117	4.0 (1.0)	80	19	4.0 (2.0)	63	4.13 (.77)	Met
23) …if the carer is satisfied with the outcome of any assessments that they, or the person they care for, has had? (if appropriate)	136	4.0 (1.0)	67	117	4.0 (1.0)	67	19	4.0 (2.0)	69	N/A	Not met

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR)	Consensus rate* (%)	Total sample mean (SD)	Criteria**
29) …if the carer feels they are currently getting enough support, or know where to access it when they are ready?	136	5.0 (1.0)	87	117	5.0 (1.0)	90	19	5.0 (2.0)	69	4.41 (.71)	Disagreement
30) …if the carer has received increasing support when the level of care they provide has increased?	136	4.0 (1.0)	78	117	4.0 (1.0)	80	19	4.0 (2.0)	68	4.08 (.76)	Disagreement
TOPIC 8: END OF LIFE AND PLANNING **How important is it to ask…**											
31)…if the carer knows the wishes and preferences of the person they care for and they have been written down and shared e.g. Advance Care Planning (ACP) document?	136	4.0 (1.0)	82	117	4.0 (1.0)	86	19	4.0 (1.0)	58	4.21 (.77)	Disagreement
32)…if the carer knows what support is available to them before and after the death of the person that they care for?	136	4.0 (1.8)	74	117	4.0 (1.0)	79	19	3.0 (1.0)	42	4.03 (.83)	Disagreement

	Total sample (N)	Total sample median (IQR)	Consensus rate* (%)	Staff (N)	Staff median (IQR)	Consensus rate* (%)	Family caregivers (N)	Family caregivers median (IQR)	Consensus rate* (%)	Total sample mean (SD)	Criteria**
33)…if the carer needs advice on any legal matters? (e.g. arranging power of attorney).	136	4.0 (1.0)	73	117	4.0 (1.0)	74	19	4.0 (1.0)	68	4.04 (.85)	Disagreement

**Consensus rate – Percentage of respondents who rated the item 4 'Very important' or 5 'Extremely important'.*

*** Criteria - If 70% met, retain item, if not met then remove item, if disagreement between cohorts then, re-rate item.*

Appendix 28: Consolidated criteria f reporting qualitative studies (COREQ) - 32-item checklist (Tong, Sainsbury and Craig, 2007).

No item	Guide questions/Description	Outcome	Reported in Chapter(s)
Domain 1: Research Team and reflexivity			
Personal characteristics			
1.Interviewer/facilitator	Which author/s conducted the interview or focus group?	EM conducted all interviews	Methods (Chapter 5, section 5.6.5)
2. Credentials	What were the researcher's credentials? e.g. PhD, MD	Study conducted for PhD Clinical Nurse Specialist (CNS) for stroke in previous role	Title page Preface section of the thesis
3. Occupation	What was their occupation at the time of the study?	PhD student	Title page
4. Gender	Was the researcher male or female?	Female (apparent from student's name)	Title page
5. Experience and training	What experience or training did the researcher have?	Novice researcher, however attended internal and external training sessions due to being a PhD student	Title page
Relationship with participants			
6. Relationship established?	Was a relationship established prior to study commencement?	No previous relationship was established between the participants and the researcher; however, rapport was built during the initial conversations with participants.	Methods (Chapter 5)

7. Participant knowledge of interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research.	Participants knew of Ems background as clinical specialist nurse (CNS) for stroke and her interest in the research topic.	Methods (Chapter 5)
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic.	EM's prior experience as CNS for stroke was clearly described	Preface section of thesis
Domain 2: Study design			
Theoretical framework			
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis.	Action Research (AR) principles provided methodological underpinning of this study	Methodology (Chapter 4)
Participant selection			
10. Sampling	How were the participants selected? e.g. purposive, convenience, consecutive, snowball	Self-selected, purposive sampling was employed.	Methods (Chapter 5)
11. Method of approach	How the participant was approached? e.g. face-to-face, telephone, mail, email.	Participants were approached face to face through the stroke support groups and through the community stroke coordinators during home visits.	Methods (Chapter 5)
12. Sample size	How many participants were in the study?	16 stroke family caregivers (phase one) 5 stroke family caregivers (phase three)	Methods and findings (Chapter 6) Methods and findings (Chapter 8)
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Refusal to participate unknown due to method of recruitment	Methods and findings (Chapter 6 and 8)
Setting			

14. Setting of data collection	Where was data collected? e.g. home, clinic, workplace.	Home, national stroke charity support group venue, café, University office and one phase three interview was conducted over the telephone as preferred by the participant.	Methods and findings (Chapter 6 and 8)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	One family caregiver (daughter) was interviewed in front of a stroke survivor (mother) during the evaluation phase. During the exploratory phase all participants were interviewed alone.	Methods and findings (Chapter 8) Methods (Chapter 5, 5.6.5)
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date.	Summaries of participant demographic data are presented in tables within the findings Chapter	Methods and Findings (Chapter 6 and 8)
Data collection			
17. Interview guide	Were questions, prompts, guides provided by the authors?	An interview guide was used during the semi-structured interviews in the first part of the exploratory phase and evaluation phase.	Methods (Chapter 5) (Example see Appendix 14)
18.Repeat interviews	Were repeat interviews carried out? If yes, how many?	No repeat interviews were carried out	Methods and findings (Chapter 6 and 8)
19. Audio-visual recording	Did the research use audio or visual recording to collect data?	Interviews were audio recorded	Methods (Chapter 5)
20.Field notes	Were field note made during and /or after the interview or focus group?	Reflective notes were made following each interview in a diary	Methods (Chapter 5)

21. Duration	What was the duration of the interviews of focus group?	The duration (range) of the interviews was stated within each findings chapter.	Methods and findings (Chapter 6 and 8)
22. Data Saturation	Was data saturation discussed?	Exploratory phase (part one) – Data saturation was reached after interviewing 16 participants. Evaluation phase – not in accordance with purpose of the pilot study as number of family caregivers participating in the pilot study, pre-determined.	Methods (Chapter 5- 5.6.2) Methods and findings (Chapter 6) Methods (Chapter 5) Methods and findings (Chapter 8)
23. Transcripts returned	Were transcripts returned to participants for comment and /or correction?	No, since not in accordance with methodology. However, two members of the supervisory team undertook independent analysis (half of the transcripts). Furthermore, findings were shared electronically to members of the VAG in both phase one and phase three for their comments.	Methods (Chapter 5)
Domain 3: analysis and findings			
Data analysis			
24. Number of data coders	How many data coders coded the data?	Data coded by EM with supervisors as independent auditors. A summary of the findings distributed	Methods (Chapter 5)

		electronically amongst the VAG members.	
25. Description of the coding tree	Did authors provide a description of the coding tree?	An overview of the main themes and sub-themes provided in Chapter 6 (Table 20) and Chapter 8 (Section 8.6.3)	Methods and findings (Chapter 6 and 8)
26. Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data	Methods (Chapter 5) Methods and findings (Chapter 6 and 8)
27. Software	What software, if applicable was used to manage the data?	Nvivo software was used to assist with data management.	Methods (Chapter 5)
28. Participant checking	Did participants provide feedback on the findings?	No, not in accordance with methodology.	Methods (Chapter 5)
Reporting			
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number?	Yes, participant quotes were provided to contextualise all themes with inclusion of unique numbers given to participants during the interviews and not their real names.	Methods and findings (Chapter 6 and 8)
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Findings contextualised with participant quotes and later related to existing literature.	Methods and findings (Chapter 6 and 8) Discussion (Chapter 9)
31. Clarity of major themes	Were major themes clearly presented in the findings?	Major themes are clearly presented in the findings and also synthesized with existing literature.	Methods and findings (Chapter 6 and 8) Discussion (Chapter 9)
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Minor themes are described and synthesised with existing literature	Methods and findings (Chapter 6 and 8)

			Discussion (Chapter 9)

Appendix 29: Guidance on Conducting and Reporting Delphi Studies (CREDES) (Jünger et al., 2017)

Recommendations	Outcome	Reported in Chapter (s)
Rationale for choice of Delphi technique		
1. Justification The choice of the Delphi technique as a method of systematically collating expert consultation and building consensus needs to be well justified. When selecting the method to answer a particular research question, it is important to keep in mind its constructivist nature.	Rationale for selecting the Delphi technique has been provided.	Methods (Chapter 5, section 5.7.1)
Planning and design		
2. Planning and process The Delphi technique is a flexible method and can be adjusted to the respective research aims and purposes. Any modifications should be justified by a rationale and be applied systematically and rigorously.	The Delphi technique was modified in this study from the classical Delphi. Round 1 was replaced with interviews. Additionally, items that did not meet the pre-determined criteria were eliminated during data analysis. Furthermore, a consultation with members of the VAG was undertaken to prioritise the final items for inclusion in the CAT-S.	Methods (Chapter 5, section 5.7.1, 5.7.7, 5.7.8, and Table 16).
3. Definition of consensus Unless not reasonable due to the explorative nature of the study, an a priori criterion for consensus should be defined. This includes a clear and transparent guide for action on (a) how to proceed with certain items or topics in the next survey round, (b) the required threshold to terminate the Delphi process and (c) procedures to be followed when consensus is (not) reached after one or more iterations.	A summary of the pre-determined criteria used to accept, reject or re-rate an item is provided.	Methods (Chapter 5, section 5.7.7 and Table 16)

Study conduct		
4. Informational input All material provided to the expert panel at the outset of the project and throughout the Delphi process should be carefully reviewed and piloted in advance in order to examine the effect on experts' judgements and to prevent bias	Piloting of all the survey instruments was undertaken. Furthermore, all the survey instruments were reviewed by VAG members as well as members of the supervisory team.	Methods (Chapter 5, Figure 7)
5. Prevention of bias Researchers need to take measures to avoid directly or indirectly influencing the experts' judgements. If one or more members of the research team have a conflict of interest, entrusting an independent researcher with the main coordination of the Delphi study is advisable.	No conflict of interest was declared by research student, the supervisory team or VAG members	Methods (Chapter 5)
6. Interpretation and processing of results Consensus does not necessarily imply the 'correct' answer or judgement; (non) consensus and stable disagreement provide informative insights and highlight differences in perspectives concerning the topic in question.	Findings have been tabulated and descriptive statics used to explore the mean and interquartile range of each item including the level of consensus.	Findings (Chapter 7, Table 23) and Appendix 27 and 28.
7. External validation It is recommended to have the final draft of the resulting guidance on best practice in palliative care reviewed and approved by an external board or authority before publication and dissemination	Initial external validation of the items on the CAT-S was undertaken with members of an expert panel.	Methods and findings (Chapter 7, section 7.10)

Reporting		
8. Purpose and rationale The purpose of the study should be clearly defined and demonstrate the appropriateness of the use of the Delphi technique as a method to achieve the research aim. A rationale for the choice of the Delphi technique as the most suitable method needs to be provided.	The overall aim of the study has been outlined. A rationale for choice of Delphi technique has been provided.	Introduction (Chapter 1) Methods (Chapter 5 section 5.7.1)
9. Expert panel Criteria for the selection of experts and transparent information on recruitment of the expert panel, sociodemographic details including information on expertise regarding the topic in question, (non) response and response rates over the ongoing iterations should be reported.	Inclusion and exclusion criteria for staff and family caregivers are provided including the criteria chosen to select the expert panels. Demographic details of stroke family caregivers have been provided and clinical experience for the staff Unable to calculate response rate reliably due to the reliance on gatekeepers to distribute the survey.	Methods (Chapter 5 section 5.7.4) Methods and findings (Chapter 7, Tables 21, 22, 25 and 26)
10. Description of the methods. The methods employed need to be comprehensible this includes information on preparatory steps (How was available evidence on the topic in question synthesised?), piloting of material and survey instruments, design of the survey instrument(s), the number and design of survey rounds, methods of data analysis, processing and synthesis of experts' responses to inform the subsequent survey	A detailed account of the methods employed in the study has been provided.	Methods (Chapter 5)

round and methodological decisions taken by the research team throughout the process. 11. Procedure Flowchart to illustrate the stages of the Delphi process, including a preparatory phase, the actual 'Delphi rounds', interim steps of data processing and analysis, and concluding steps.	A flowchart demonstrating the Delphi process in this study has been presented.	Methods (Chapter 5, Figure 7)
12. Definition and attainment of consensus It needs to be comprehensible to the reader how consensus was achieved throughout the process, including strategies to deal with non-consensus	A summary of the pre-determined criteria used to accept, reject or re-rate an item is provided. A summary of how consensus was achieved	Methods (Chapter 5; Table 16) Methods and findings (Chapter 7)
13. Results. Reporting of results for each round separately is highly advisable in order to make the evolving of consensus over the rounds transparent. This includes figures showing the average group response, changes between rounds, as well as any modifications of the survey instrument such as deletion, addition or modification of survey items based on previous rounds	Findings from each round are presented separately. Tables showing the mean and inter-quartile range of each item are provided.	Methods and findings (Chapter 7, section 7.4 and 7.6) Appendix 25 and 26.
14.Discussion of limitations Reporting should include a critical reflection of potential limitations and their impact on the resulting guidance.	A summary of the potential limitations is presented in the thesis	Study strength and limitations (Chapter 10)
16. Publication and dissemination The resulting guidance on good practice in palliative care should be clearly identifiable from the publication, including recommendations for transfer into practice and implementation. If the publication does not allow for a	A detailed presentation of how the CAT-S was developed has been provided in the thesis.	Methods and findings Chapter 8 (section 8.2) Chapter 10

detailed presentation of either the resulting practice guidance or the methodological features of the applied Delphi technique, or both, reference to a more detailed presentation elsewhere should be made (e.g. availability of the full guideline from the authors or online; publication of a separate paper reporting on methodological details and particularities of the process (e.g. persistent disagreement and controversy on certain issues). A dissemination plan should include endorsement of the guidance by professional associations and healthcare authorities to facilitate implementation.	Recommendations for practice that have been developed based on the findings from this study are provided within the thesis The research student has plans to publish the findings from this study in a high impact, peer reviewed multidisciplinary journal.	Recommendations and conclusions (Chapter 10, section 10.2.1)

Appendix 30: Top 10 items ranked by cohort mean (family caregivers)

Items not highlighted were top ranked by both staff and family caregivers. Items highlighted are those that were top ranked by family caregivers only.

Rank	Item	Topic* (R1 item number)	N	Consensus rate** (%)	Mean (SD)
1	To ask if the carer feels that professionals involve them in decision making by seeking their knowledge and expertise about the care needed by the person they care for?	3 (18)	19	90	4.52 (.69)
2	To ask if the carer feels able to support the psychological or emotional needs of the person they care for?	2 (13)	19	79	4.47 (.84)
3	To ask if the carer has a named person or number to call with any concerns about the person they care for?	2 (15)	19	89	4.42 (.69)
4	To ask if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	4 (21)	19	84	4.42 (.76)
5	To ask if the carer requires support to provide personal care (including toileting, washing and dressing, feeding) to the person that they care for?	2 (10)	19	69	4.31 (.94)
6	To ask if the carer feels able to manage and cope with the behaviour of the person they care for?	2 (12)	19	84	4.31 (.74)
7	To ask if the carer feels they are receiving the support they need from professionals at the time they need it?	3 (17)	19	74	4.31 (1.00)
8	To ask if the carer feels they are currently getting enough support, or know where to access it when they are ready?	7 (39)	19	69	4.31 (.94)
9	To ask if the carer has responsibility for making decisions about the care of the person they care for, as a result of the stroke?	1 (6)	19	79	4.26 (.80)
10	To ask if the carer is accessing any of the support or assistance available to carers?	1 (7)	19	68	4.26 (.93)

**Topic 1- Caring situation, Topic 2- Caring situation, Topic 3 - Relationship with health and social care professionals, Topic 4 - Respite and emergency care, Topic- 6 Carer's health and well-being, Topic 7- Support for the carer, Topic 8 - End of life and planning.*

***Consensus rate – percentage of cohort sample (family caregivers) who rated the item 4 'Very important' or 5 'Extremely important'*

Appendix 31: Top 10 items ranked by cohort mean (staff)

Items not highlighted were top ranked by both staff and family caregivers. Items highlighted are those that were top ranked by staff only.

Rank	Item	Topic* (R1 item number)	N	Consensus rate**(%)	Mean (SD)
1	To ask if the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, caring for grandchildren)	1 (4)	117	94	4.74 (.55)
2	To ask if the carer feels able to manage and cope with the behaviour of the person they care for?	2 (12)	117	94	4.70 (.57)
3	To ask if the carer needs any training to provide care safely, such as lifting, and handling or equipment use training?	2 (9)	117	94	4.65 (.58)
4	To ask if the carer requires support to provide personal care (including toileting, washing and dressing, feeding) to the person that they care for?	2 (10)	117	93	4.61 (.64)
5	To ask if the carer has a named person or number to call with any concerns about the person they care for?	2 (15)	117	90	4.56 (.67)
6	To ask if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital?	4 (21)	117	90	4.56 (.67)
7	To ask if the carer understands the expected recovery from stroke for the person they are caring for?	1 (5)	117	91	4.55 (.71)
8	To ask if the carer feels able to support the psychological or emotional needs of the person they care for?	2 (13)	117	92	4.55 (.64)
9	To ask if the carer is accessing any of the support or assistance available to carers?	1 (7)	117	90	4.51 (.70)
10	To ask if the carer has responsibility for making decisions about the care of the person they care for, as a result of the stroke?	1 (6)	117	87	4.43 (.78)

**Topic 1- Caring situation, Topic 2- Caring situation, Topic 3 - Relationship with health and social care professionals, Topic 4 - Respite and emergency care, Topic- 6 Carer's health and well-being, Topic 7- Support for the carer, Topic 8 - End of life and planning.*

***Consensus rate – percentage of cohort sample (staff) who rated the item 4 'Very important' or 5 'Extremely important'*

Appendix 32: Final 30 items ranked by total sample mean under each topic in Round 2

Rank	Topic item (R1 item number)	N	Consensus rate* (%)	Mean (SD)
	TOPIC 1: CARING SITUATION			
1	…if the carer has other demands on their time in addition to their caring role? (e.g. working, volunteering, studying, young family, caring for grandchildren) **(4)**	136	90	4.64 (.70)
2	…if the carer understands the expected recovery from stroke for the person they are caring for? **(5)**	136	88	4.50 (.76)
3	…if the carer is accessing any of the support or assistance available to carers? **(7)**	136	87	4.47 (.74)
4	…if the carer has responsibility for making decisions about the care of the person they care for, as a result of the stroke? **(6)**	136	86	4.41 (.78)
5	...if the carer lives in the same house as the person they care for? **(2)**	136	75	4.22 (.89)
	TOPIC 2: CARING ROLE			
1	...if the carer feels able to manage and cope with the behaviour of the person they care for? **(12)**	136	93	4.64 (.61)
2	…if the carer needs any training to provide care safely, such as lifting, and handling or equipment use training? **(9)**	136	91	4.58 (.64)
3	**…**if the carer requires support to provide personal care (including toileting, washing and dressing, feeding) to the person that they care for? **(10)**	136	90	4.57 (.69)
4	...if the carer feels able to support the psychological or emotional needs of the person they care for? **(13)**	136	90	4.54 (.67)
5	…if the carer has a named person or number to call with any concerns about the person they care for? **(15)**	136	90	4.54 (.64)
6	…if the carer needs support to assist with any aspect of rehabilitation of the person they care? **(11)**	136	81	4.26 (.78)
7	…if the carer is supporting the person they care for with their medications? **(8)**	136	54	4.03 (.92)
	TOPIC 3: RELATIONSHIP WITH HEALTH AND SOCIAL CARE PROFESSIONALS			
1	…if the carer feels that professionals involve them in decision making by seeking their	136	84	4.29 (.75)

	knowledge and expertise about the care needed by the person they care for? **(18)**			
2	…if the carer feels they are receiving the support they need from professionals at the time they need it? **(17)**	136	86	4.28 (.73)
	TOPIC 4: RESPITE AND EMERGENCY CARE			
1	…if the carer has planned what should happen in an emergency if they were unable to provide care e.g. if they become ill or go into hospital? **(21)**	136	89	4.54 (.74)
2	…if the carer would like support with a break from caring such as using a sitting service in their home for a few hours or to use respite care for a longer break? **(19)**	136	85	4.30 (.74)
	TOPIC 5: FINANCIAL SUPPORT AND ASSESSMENTS			
1	…if the carer knows of and has applied for all appropriate funding such as benefits, mobility schemes? (**23)**	136	83	4.22 (.70)
2	…if the carer has had a carer's assessment? **(27)**	136	77	4.13 (.77)
3	…if the carer has any financial worries? **(22)**	136	71	4.03 (.80)
4	…if the carer knows what a carer's assessment is? **(26)**	136	73	3.99 (.85)
	TOPIC 6: CARER'S HEALTH AND WELL-BEING			
1	…if the carer would like help to cope with any aspects of their caring role? **(31)**	136	86	4.36 (.71)
2	…if the carer is able to balance their own health needs with the demands of caring? **(33)**	136	83	4.32 (.76)
3	…if the carer would like to talk to someone about their emotional well-being? **(30)**	136	78	4.16 (.78)
4	...if the carer would like to talk to someone about their own physical well-being? **(29)**	136	73	3.95 (.74)
	TOPIC 7: SUPPORT FOR THE CARER			

1	…if the carer feels they are currently getting enough support, or know where to access it when they are ready? **(39)**	136	87	4.41 (.71)
2	…if the carer has received increasing support when the level of care they provide has increased? **(40)**	136	78	4.08 (.76)
3	…if the carer has received information about the carer support available in their area? (e.g. carers centre, carer support groups) **(38)**	136	77	4.01 (.73)
	TOPIC 8: END OF LIFE AND PLANNING			
1	**…**if the carer knows the wishes and preferences of the person they care for and they have been written down and shared e.g. Advance Care Planning (ACP) document? **(41)**	136	82	4.21 (.77)
2	**…**if the carer needs advice on any legal matters? (e.g. arranging power of attorney) **(43)**	136	73	4.04 (.85)
3	**…**if the carer knows what support is available to them before and after the death of the person that they care for? **(42)**	136	74	4.03 (.83)

**Consensus rate: percentage of respondents who rated the item 4 'Very important' or 5 'Extremely important'*

Appendix 33: Letter from Liverpool Clinical Commissioning Group (CCG) confirming funding to pilot the CAT-S.

NHS
Liverpool
Clinical Commissioning Group

NHS Liverpool CCG
The Department Lewis's Building
Renshaw Street
Liverpool
L1 1JX
Tel: 0151 296 7726
Email:
dave.horsfield@liverpoolccg.nhs.uk

31.01.2018

Professor Barbara Jack
Evidence-Based Practice Research Centre (EPRC)
Edge Hill University
Faculty of Health & Social Care
St Helens Road
Ormskirk
L39 4QP

Dear Professor Jack

Liverpool Clinical Commissioning Group (LCCG) RCF Award 2017/18

Thank you for your application for funding from the recent LCCG RCF Call.

On behalf of the LCCG RCF Funding Panel, I have pleasure in offering you the 'Grant Holder' a grant of **£18,637** inclusive of VAT, for the research proposal {**Pilot and evaluation of the Carers' Alert Thermometer adapted for carers of stroke survivors (CAT-S) and development of a bid to conduct a trial of CAT across long-term and progressive conditions.**} ("the Research"), a copy of which is attached as Appendix 1 to the letter. The grant shall take effect from **31st January 2018 and shall continue until 31st December 2018** subject to agreed timescale amendments in writing unless terminated in accordance with paragraph 6 below.

The terms and conditions of the offer as follows:

1. Payment shall be made via 2 payments as highlighted in Appendix 2.

2. Please ensure Purchase Order numbers are quoted on the invoice, otherwise the invoices will not be paid.

3. Offers of funding are conditional on you obtaining any necessary ethical approval and identifying a sponsor (as defined in the Department of Health Research Governance Framework and/or the UK Clinical Trials Regulations as appropriate) for the Research.

4. Funding is to be used solely in respect of the specific study for which the grant is awarded. That can only be changed with the specific prior approval of the CCG R&D Department before any expenditure incurred on the amended research. We reserve the right to withhold a grant or require repayment if the work undertaken is not the work for which the grant was approved.

5. Any proposed amendments to the use of funding (virement of funds) during the course of the project must be referred to the LCCG R&D Manager for approval prior to such changes being initiated.

6. Any part of the grant that is not required for the purpose approved will be refunded to the CCG for use in further projects supported by the CCG.

7. The start of the project may only be delayed with LCCG R&D Department agreement.

8. A schedule for submitting progress reports and agreeing dates for progress meetings should be agreed with the R&D Manager and you the researcher.

9. A discussion regarding any NIHR bids and potential hosting arrangements should be had with the CCG R&D Manager well in advance of submission.

10. The CCG R&D Strategy Group shall be kept informed of the progress made on the study and Grant Holders will be asked to provide progress reports in the format available from the CCG R&D Manager until the final report/bid is produced for the research project. Failure to forward such reports will result in a delay in the forwarding of the next instalment of the grant.

11. Grant holders should ensure that any publications, presentations or any other printed materials that you produce about the work for which you have received funding, carry acknowledgements to the financial support of NHS Liverpool CCG. Grant Holders are obliged to furnish the LCCG R&D Strategy Group with copies of any publications that arise from their research project, including presentations at conferences, at least four weeks in advance of the submission of such proposed publication or presentation to a journal editor or other third party. If you want to acknowledge our grant in a press release or any other type of media coverage, you should contact the CCG R&D Department.

12. The Grant Holder agrees to treat any information that it learns about the CCG in the course of undertaking the Research as confidential.

13. The Grant holder grants to NHS Liverpool CCG a non-exclusive, royalty-free license to use intellectual property generated as a result of this funding (the IPR). Should the Grant Holder wish to use the IPR for any other reason than the furtherance of research, it shall notify LCCG of the same stating this intended purpose.

All published papers and conference abstracts arising from the evaluation will include named members of the project research team that fulfil criteria for authorship. They will be circulated to all named authors for comment prior to submission and will adhere to the recognised international guidelines for named authorship (International Committee of Medical Journal Editors IME author & contributions guide 2009: http://www.icmje.org/ethical_1author.html)

For the avoidance of doubt all Background Intellectual Property used in connection with the Project shall remain the property of the party introducing the same. Neither party will make any representation or do any act which may be taken to indicate that it has any right, title or interest in or to the ownership or use of any Background Intellectual Property belonging to the other party except under the terms of this Agreement. Each party acknowledges and

confirms that nothing contained in this Agreement shall give it any right, title or interest in or to the Background Intellectual Property of the other party save as granted by this Agreement.

Each party shall grant to the other party, to the extent it is able to do so, an irrevocable royalty free licence to use such of its Background Intellectual Property, and any Foreground Intellectual Property belonging to it, as may be necessary for delivery of the Project.
All rights to Foreground Intellectual Property created by either of the parties in the performance of this Agreement shall belong to Edge Hill University.

Edge Hill University will grant to Liverpool Clinical Commissioning Group an irrevocable royalty free non-exclusive licence to use the Foreground Intellectual Property

14. The LCCG accept no responsibility or liability, financial or otherwise, arising from the Research.

All communication with respect to this grant shall in the first instance be with the LCCG R&D Manager, Kirsty Pine on telephone number 0151 296 7451 or email Kirsty.pine@liverpoolccg.nhs.uk.

If these terms are acceptable, please have two copies of the agreement signed by an authorised signatory of your University and return one copy to the R&D Manager at the above address.

Yours sincerely

Dave Horsfield
Digital, Innovation & Research Lead
NHS Liverpool CCG
Enc.

For and on behalf of
(The Grant Holder)

Name:……..

Date:……..

Acknowledged by the Principal Investigator

Name:……..

Date:……..